The London School of Economics and Political Science

The well-being and quality of life of men and women of different ages providing care for a relative with dementia

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Declaration of Authorship

I certify that the thesis I have presented for examination for the PhD degree of the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it).

I warrant that this authorisation does not, to the best of my belief, infringe the rights of any third party.

I declare that my thesis consists of 89,950 words.

Klara Lorenz

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Abstract

This thesis examined if and how well-being and quality of life of people providing care for a relative with dementia are affected, with particular focus on carer gender and age. Mixed methods research utilised data from three studies in England (MODEM, START and SHIELD-CSP-RYCT) and 25 interviews with carers of people with dementia who also participated in the MODEM cohort study.

The qualitative interviews with family carers focused on what carers understood by well-being in the context of dementia care. The 'relationship with the care-recipient', 'support from family and friends', 'safety and security', 'successful coping mechanisms', 'external facilitators to well-being' and 'carer health' were identified as key factors influencing carer well-being and provide an understanding of how carer well-being could be supported.

Quantitative analysis of factors influencing carer well-being and quality of life over time pointed towards gender differences in health-related quality of life, happiness and life satisfaction. Women were likely to experience worse outcomes than men. Carer age was found to influence mental health, but results were inconclusive.

Finally, quantitative analyses investigated factors influencing the time that carers spent on different care tasks. Women were likely to spend more time on personal care (ADL tasks) and instrumental activities of daily living (IADLs) than men. No age difference could be found in relation to any of the various tasks investigated. This suggests no difference by age in how much time carers spent on personal care, IADLs, supervision or total care. Aspects influencing care intensity provide important insights on aspects that can help to reduce care intensity and increase carer well-being.

The thesis highlights the need for recognition of carers as a heterogeneous group, whose characteristics, such as age and gender, need to be taken into consideration when designing and implementing interventions and in conducting research aiming to support carers.

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List of abbreviations

ADCS-ADL	Alzheimer's Disease Cooperative Study – Activities of Daily Living Inventory
ADL	Activities of Daily Living
AIC	Akaike information criterion
APS	Annual Population Survey
BADLS	Bristol Activities of Daily Living Scale
CDC	Centers for Disease Control and Prevention
CDR	Clinical Dementia Rating
CED-D	Center for Epidemiologic Studies Depression Scale
COPE	COPE Inventory
QCPR	Quality of Caregiver-Patient Relationship
CSRI	Client Service Receipt Inventory
ELSA	English Longitudinal Study of Ageing
GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
HSE	The Health Survey for England
HSQ	Health Status Questionnaire
IADL	Instrumental Activities of Daily Living
MAR	Data missing at random
MCAR	Data missing completely at random
MCTS	Modified Conflict Tactics Scale
MMSE	Mini-Mental State Examination
MODEM	Modelling Outcome and Cost Impact of Intervention for Dementia
NICE	National Institute for Health and Care Excellence
NMAR	Data not missing at random
NPI	Neuropsychiatric Inventory
OARS	Older American Resources and Services Social Resources Scale
OECD	Organisation for Economic Cooperation and Development
ONS	Office for National Statistics
PANAS	Positive and Negative Affect Schedule
PGI	Personal Growth Index
PHQ-9	Patient Health Questionnaire
PWB	Personal Well-Being Scale
QoL-AD	Quality of Life – Alzheimer's Disease
RSSE	Revised Scale for Caregiving Self Efficacy
RUD	Resource Utilization in Dementia
SHIELD-CSP-RYCT	The Support at Home: Interventions to Enhance Life in Dementia: Carers Supporter Programme "Remembering Yesterday Caring Today"
START	StrAtegies for RelaTives study
WHO	World Health Organization
WEMWBS	Warwick-Edinburgh Mental Well-Being Scale
ZBI	Zarit Burden Inventory

Chapter 1

Introduction

1.1 The growing number of people with dementia requiring support

Following a diagnosis of dementia many people have to come to terms with the illness and what it means for their lives. However, a dementia diagnosis hardly ever only affects the person receiving it; it also affects people in their immediate environment, their partners, families and friends. As the illness progresses, people with dementia require support in many aspects of their lives. Traditionally, family is the first port of call. In many cases, spouses and adult children help with emerging needs (Finch & Groves, 1980, p.496). At first, family members tend to support their relatives with instrumental activities of daily living, such as helping with transportation, shopping or cleaning (OECD/ European Commission, 2013). Over time, this initial bit of help can grow into full-time care. This may include the provision of personal care tasks, such as helping the person with dementia with dressing, eating, washing or toileting (OECD/ European Commission, 2013). Progressive cognitive impairment, characteristic of all dementias, means that people with dementia are likely to require increasing amounts of supervision as the illness progresses. Supervision can be defined as the presence of other people to ensure that people with dementia are safe and comfortable even when no specific hands-on support is required (Wimo et al., 2002). Needs of the person with dementia are likely to change over time as the illness progresses, in addition potential development of neuropsychiatric disorders and behavioural changes may require the relative to adapt and develop new skills over time (De Vugt & Verhey, 2013).

In 2015, an estimated 850,000 people with dementia lived in England. By 2025 this number is set to rise to over one million, and by 2051 over two million people are expected to live with dementia. This estimate assumes constant age-specific prevalence rates, which means that demographic ageing is the driving force for the growth in numbers (Prince et al., 2014, p.viii). Dementia has been described as ‘the leading chronic disease contributor to disability and need for care’ (Wimo et al., 2013b, p.1). In the UK, most people with dementia live in the community (61.3%) and many are primarily supported by their families (Prince et al., 2014, p.54).

1.2 Family carers require attention

Relatives tend to gradually grow into the carer role as needs emerge. The effort and support put into 'maintain[ing], continue[ing] and repair[ing]' someone's world, paired with 'feelings of affection and responsibility' for their well-being are all part of definitions of care and ultimately a description of the practical and emotional support provided by family members (Cancian & Oliker, 2000; Tronto, 1993; Madörin, 2006; Thelen, 2014; Winker, 2015). Yet, spouses and adult children, who provide the majority of unpaid support in families, sometimes experience difficulty identifying themselves in their caring roles, as the care they provide only seems to be a natural extension of their perceived spousal or filial duties (Carers Trust, 2014; Carretero et al., 2009; Pinquart & Sörensen, 2004). In this thesis, the term family carer, unpaid carer or carer will be used interchangeably to refer to family members supporting people with dementia without substantial financial reimbursement. The use of family carer or carer is consistent with the preferences expressed in a consultation of carers by Farina and colleagues (2017) to distinguish between unpaid family care and 'paid' or 'formal' care.

The provision of unpaid care for people with dementia in the community has often been found to be time-intensive, and even though carers express satisfaction from doing something good and right by supporting their relatives, many family carers also experience difficulties when the social demeanour of their relatives changes and the care tasks become more demanding (Pretorius, Walker & Heyns, 2009; Sampson & Clark, 2015). Carers may also experience something akin to grief when the cognitive decline causes care-recipients no longer to be able to maintain their previously ascribed social roles (Shuter, Beattie & Edwards, 2014). This, in combination with the long hours many carers provide to ensure that their relatives are safe and comfortable, can lead to a neglect of their own needs and result in negative outcomes for the carer. Research has shown that carers of people with dementia are likely to experience challenges, such as social isolation, and physical and mental health issues (Ory et al., 1999; Vitaliano, Zhang & Scanlan, 2003; Pinquart & Sörensen, 2007; Larkin, Henwood & Milne, 2018). Substantial care needs lead many relatives of working age to cut down on working hours or to leave employment altogether (King et al., 2014). Reduced employment in turn may mean that carers do not contribute to pensions schemes, which can leave them in a vulnerable position later in life (King & Pickard, 2014). The contribution that unpaid carers provide to society is substantial. The cost of unpaid care provided for people with dementia in 2014 has been estimated to be £11.6 billion, which amounts to 44.1% of total costs associated with dementia (Prince et al., 2014,

p.xv). While the exact estimation of the cost of unpaid care depends on the costing approach chosen, the provision of unpaid care remains a substantial factor in the overall cost of dementia whatever the methodology (e.g. replacement time or opportunity cost) (Oliva-Moreno et al., 2017; Schaller et al., 2015) .

1.3 Government policy focusing on well-being

Government policy emphasises the provision of care in the community, which means enabling people to live in their own homes for as long as possible (Finch & Groves, 1980; Titmuss, 1976; Care Act, 2014). The social services funding structure, in part, supports the focus on community care. Social care in England, in contrast to health care, is means tested and not necessarily available free of charge. This means that people with social care needs and their carers are required to undergo a needs assessment as well as an assessment of their financial circumstances before social services can start to provide services (SCIE, 2014; NHS, 2018). People with a need for social services support, but sufficient financial means are likely to have to contributed towards the receipt of services. Where people, with the help of paid and unpaid care, can remain in their own home, the value of their property will not be considered. However, where care needs exceed the support that can be provided in the community, the value of people's home is likely to be counted towards the costs of care. For this reason, many families make an effort to support their relatives at home as long as possible in an attempt to save these resources for future need, but most people with dementia and their families also prefer living at home (YouGov, 2012; Alzheimer's Society, 2018).

However, as outlined above, enabling people with substantial care needs to live well in the community requires substantial effort and support that is usually provided by one member of the family, sometimes with support from other family members or paid services. The difference in care commitment by carers supporting a relative with dementia in the community and those supporting a person with dementia in institutional care settings has been recognised (Pot, Deeg & Van Dyck, 1997; Borsje et al., 2016; Bleijlevens et al., 2015).

In recognition of the growing number of people living with dementia and the growing number of dementia carers, the Labour government, in 2009, initiated England's first National Dementia Strategy termed *'Living well with dementia'* (Department of Health, 2009). This was followed by David Cameron's *Prime Minister's Challenge* in 2012, which was updated in 2015. The first *Challenge*, aiming for tangible outcomes by 2015, focused on three key areas: 'driving improvement in

health and care, creating dementia friendly communities that understand how to help [and] better research' (Department of Health, 2012, p.5). The strategy also specifically recognised the need to support carers. It emphasised the importance of availability of care support, breaks from caring and psychological support (Department of Health, 2012, p.10). The 2015 *Challenge* further built on these points, aiming to improve public awareness, access to diagnosis, meaningful care and support following diagnosis, training of health workers, research opportunities and to create a dementia friendly society. The 2015 *Challenge* also recommended that carers should be supported through 'opportunity for respite, education, training, emotional and psychological support' in order to strengthen carers' ability to cope and to enable them 'to have a life alongside caring' (Department of Health, 2015, p.7). As part of the implementation of the Care Act 2014, carers' right 'to an assessment of their eligible needs' was highlighted as a crucial outcome in the *Dementia Challenge 2015*.

This Care Act, enacted in 2014, now forms the most important legal foundation for people with care needs and their carers. However, only some aspects of the Care Act, such as the above-mentioned carers' rights to an assessment by the local council, came into force in April 2015. As with the assessment of people with care needs, availability of support for unpaid carers is dependent on their needs and resources. Other parts of the Act, such as the introduction of a cap on care expenditure by individuals, have been delayed to at least 2020 (Care Act, 2014).

Another relevant piece of advice, although not legally binding, was the update of the practice guidelines by the National Institute for Health and Care Excellence (NICE) on dementia care in June 2018 (NICE, 2017b, p.6; NICE, 2018). The guidelines, in line with the Prime Minister's *Dementia Challenges*, specifically recognised carers' support needs. The NICE guidelines recommend the provision of appropriate information relevant to people's circumstances and the specific dementia diagnosis, the direction towards 'relevant services for information and support', carer involvement (where appropriate) in decision making around the needs of the person with dementia as well as the provision of 'psychoeducation and skills training' for carers (NICE, 2018, p.12, p.30). Interventions for carers should contribute to increase carers' knowledge of the illness, help to build strategies and skills to deal with behavioural changes and the demands of care, support carers to 'adapt their communication styles' to enhance communication with their relative with dementia but also to learn how to support their own physical and mental health (NICE, 2018, p.12, p.31).

However, in contrast to these apparent efforts to support people with dementia and their carers to live well, social care funding over the past decade has been cut substantially, leaving many local authorities struggling to provide the support outlined in legislation and guidelines. Since the financial crisis in 2008, government funding cutbacks have led to reductions in the services available to people with moderate care needs as well as to carers, meaning that the responsibilities falling on carers supporting people in this position are even greater (Burchardt, Obolenskaya, & Vizard, 2016, p.196). Data from the Office for National Statistics (ONS) revealed that in 2015/2016 less than £17 billion was spent on social care in total. This was lower than spending in 2005/2006 (ONS, 2017b). Furthermore, pressure on local authorities has heightened as the number of people aged 65 and above increased by 18% (1.5 million) and that of people aged 85 and older grew by 17% (nearly 200,000 people) between 2009 and 2016, which increased demand (Simpson, 2017, p.4). Yet, research found that this group (adults aged 65 and older) were particularly affected by the cuts (Burchardt, Obolenskaya, & Vizard, 2016; Fernandez, Snell & Wistow, 2013). Furthermore, funding cuts did not affect local authorities across the country equally. Areas with greater social care spending experienced a greater reduction in resources. This is the case because areas with greater needs received disproportionately more funding (Simpson, 2017, p.5). Forecasts over the next three years exploring different scenarios do not predict an improvement in the funding situation (Simpson, 2017).

The Dilnot review proposed substantial reforms of the social care system, which included capping lifetime contribution, increasing the asset threshold for support eligibility from £23,250 to £100,000 as well as standardising national eligibility criteria and revising the eligibility and assessment framework (Commission on Funding of Care and Support, 2011). However, while some of the recommendations, such as a cap on social care expenditure, were picked up in the Care Act 2014, so far they have not been implemented. This means that individuals' risk of spending substantial resources on social care have not been addressed proactively (Simpson, 2017). Furthermore, the social care Green Paper, which is expected to 'focus on care for older people' and which was due to be published in the summer of 2017, has been delayed repeatedly to its current expected release in autumn 2018 (Jarrett, 2018). In the absence of substantial reform and with increasing pressure on social care funding, unpaid carers supporting people with dementia experience growing pressure, with many not receiving support for their own needs. Where available, family carers are likely to fill the gap (Burchardt, Jones & Obolenskaya, 2018).

1.4 The gendered nature of care and the relevance of carer age

Traditionally, care fell, as any other form of unpaid work, into the realm of women (Sevenhuijsen, 1998, p.vi; Folbre, 2001, p.5; Bubeck, 1995, p.25; Browne, 2010). From looking after siblings, raising children, to supporting frail elderly family members, this was the realm of women for many centuries and it is therefore not surprising that the literature on care is dominated by a feminist discourse. The field is framed by the important work of women, such as Nancy Folbre, Janet Finch or Dulcie Groves, to name just a few (Finch & Groves, 1980; Folbre, 2001). These women made important contributions by questioning care as a solely female duty. The discourse further highlighted the differentiation into productive male labour, which stood in contrast to devalued domestic female chores. These included the provision of care tasks and arguably until today reflect the disproportionately low pay and recognition people in care-related jobs receive (Thelen, 2014, p.28).

One could argue that much has been achieved with respect to gender equality. Female employment, for example, rose from approximately 57% in 1975 to 78% in 2017 (Scott & Cleary, 2013; Roantree & Vira, 2018). However, increasing participation in the labour market is not to be confused with a fairer share in care work between men and women. Still today, women provide the bulk of unpaid care throughout their lives and are more likely to reduce employment to look after children and family members with care needs (McGuiness, 2018; Costa Dias, Elming & Joyce, 2016; ONS, 2013a; ONS, 2018). In the context of dementia care, daughters particularly experience being torn between their employment, the demands of their own family and the needs of a parent with dementia (Brimblecombe et al., 2017; Romero-Moreno, 2014; Simpson & Carter, 2013b). Sons typically provide less personal care and instead focus on managerial tasks (Campbell, 2010; Grigorovich et al., 2016; Ferrant, Pesando & Nowacka, 2014). However, the supply of filial carers is limited. Pickard (2013) projected that demand for unpaid care of older people with disabilities will not be matched by supply in the years ahead. She estimated that by 2032 there will be a shortage of 160,000 filial carers in England (Pickard, 2013, p.2).

A spike in unpaid care commitment occurs among people aged 50 and older. Women, wives or daughters play an important role and women aged 45 to 65 years were found to provide most care (Carretero et al., 2009; Colombo et al., 2011; Wimo et al., 2013b). In England women of all age groups were found to have increased the daily amount of care provided between 2000 and 2015, while the care commitment of men among the 30 to 40 year age group fell by 67%. The amount of daily care provided by

men only increased in the group aged 50 years and over, where care commitment was found to have increased by approximately 15% between 2000 and 2015 (ONS, 2016a, pp.12-13). The 2011 Census showed that in this age group more men than women provided unpaid care in England and Wales, at all levels of intensity (ONS, 2013a). Comparison of Census data over time further illustrates the growing importance of older carers. On the basis of the Censuses in 2001 and 2011, Carers UK reported that from 2001 to 2011 there was a 25% increase of carers aged 65 to 74 years. The share of carers aged 75 to 84 years and those aged 85 and above increased by 45% and 128%, respectively (Carers UK, 2015).

Carers aged 65 and above, however, are themselves at increased risk of illness and disability. The Office for National Statistics, referring to healthy life expectancy statistics, suggests that women aged 65 and above may have more care needs than men in the same age group. This is supported by recent projections suggesting that between 2015 and 2035 increasing numbers of people aged 65 and 74 years will live with multi-morbidity and predicted gains in life expectancy are likely to be spent with four or more diseases (Kingston et al, 2017). Consistent with these results, Census 2011 evidence showed that over 50% of male and female carers aged 65 and above providing 20 or more hours of care indicate that they are not in good general health (ONS, 2013a).

Dementia is an illness that predominantly affects older people. Its prevalence in the UK is estimated to increase from 1.7% among the 65-69 year old to 41.1% among those aged 95 and older (Prince et al., 2014, p.28). Increasing longevity, and particularly the increasing longevity of men, means not just that more people grow old, but also that more couples are able to grow old together, which in turn increases the potential availability of older carers (Public Health England, 2017b). The pattern of care hours shows the increasing importance of older men, who predominantly provide care for their spouses. The growing number of older husbands supporting their wives with dementia has been recognised in the literature (Baker, Robertson & Connelly, 2010; Cahill, 2000; Calasanti & King, 2007; Conde-Sala et al., 2010; Friedemann & Buckwalter, 2014; Pöysti et al., 2012; Pretorius, Walker & Heyns, 2009; Ribeiro & Paul, 2008; Sanders & Power, 2009). Studies have also focused on men's experiences of becoming a carer, taking responsibility for the household and for the couple's shared life, their experience with the provision of personal care, receipt of unpaid and paid support, their physical and mental health (McFarland & Sanders, 2000, p.370; Cahill, 2000, p.64; Ribeiro, Paul & Nogueira, 2007, p.308).

On the other hand, as Bartlett and colleagues (2018) pointed out, even though women continue to provide the majority of care throughout their lives, there is limited evidence available focusing on the female experience and needs. Among the few studies available, the focus predominantly is on women's willingness to forsake their own needs for the care of others (Eriksson, Sandberg, & Hellström, 2013).

Studies contrasting the experience of men and women providing dementia care predominantly focused on spouses, but a few also included filial carers. Overall, the message was that women experience the provision of unpaid care for a relative with dementia as more challenging. A study using a Latin-American sample reported that husbands experienced less burden than wives or filial carers, that daughters received more family support than sons but that sons provided care to relatives with fewer care needs and less cognitive impairment (Friedemann & Buckwalter, 2014, p.324). A Spanish study reported that filial carers spent fewer hours caring than spouses, but experienced greater feelings of guilt about 'doing wrong by the care-recipient', neglecting their self-care, while women felt more guilty about neglecting other people than men. This study also found that women, and in particular wives, scored higher on depression scales than men (Romero-Moreno et al., 2014).

The finding that women experience more depressive symptoms is consistent with the wider literature on care (Andreakou et al., 2016; Borsje et al., 2016; Fauth, Femia & Zarit, 2016; Gibbons et al., 2014; Lethin et al., 2017; Orgeta & Lo Sterzo, 2013; Bookwala & Schulz, 2000; Borden & Berlin, 1990; Meshefedjian et al., 1998; Pinquart & Sörensen, 2006). However, a Swedish study comparing depression, life satisfaction and loneliness among spouse carers of people with dementia did not find a statistically significant difference between men and women. The study, nevertheless, did find that women experienced greater burden than men (Pöysti et al., 2012). These results suggest that there might be differences in how men and women experience the provision of care. However, patterns remain somewhat unclear. Furthermore, age appears to play an important role, particularly among male carers.

1.5 Emergence of the research question

These findings suggest existing gender differences in how men and women experience the provision of dementia care and also show differences in the availability and willingness of carers of different ages and in different relationships to the care-recipient. Yet, the wider literature on unpaid carers for people with dementia is surprisingly gender-neutral (Bartlett et al., 2018). Bartlett and colleagues (2018) critique that even

where references are made to gender and relationships, not much further engagement with potential differences can be found. They summarized that 'it would seem that the dementia care literature is gender blind' (Bartlett et al, 2018, p.15).

The absence of a gender and age discourse, despite the acknowledgment in government statistics that unpaid dementia care is predominantly provided by women and older men, is also evident in government policies (ONS, 2013a; ONS, 2018; McGuiness, 2018). There, as stated above, the emphasis is on people with dementia and their carers to live well or, as phrased in the Care Act (2014, p.3), to 'support the well-being of carers'. Besides the absence of recognition of differences in people living with the illness or providing care, no further definition of the meaning of well-being in the context of dementia care can be found.

This raises several questions. First there are questions such as, what does it mean to be well? What is meant by the term well-being? And how can well-being be measured? When I started exploring these questions in the context of dementia care I found that the literature focusing on health policy and health economics often also referred to people's quality of life. This led to another important question: are well-being and quality of life inherently different concepts? And if not, where is the distinction?

Next, the differences between carers by gender, age and relationship require further attention. This poses questions such as are there differences in how men and women and people of different age groups understand well-being and quality of life? Does the provision of dementia care affect the well-being and quality of life of men and women, filial carers and spouses, people of different ages differently?

These questions became the motivation to write this thesis and ultimately resulted in the research question: *Does the well-being and health-related quality of life of people providing unpaid care for people with dementia in the community vary by age and gender?*

The thesis explores this overarching question with the help of five sub-questions:

1. How is carer well-being and quality of life conceptualised and measured in the literature?
2. Are the characteristics of unpaid carers in England comparable to unpaid carers of people with dementia?
3. Are there differences in how husbands, wives, daughters and sons of people with dementia experience the provision of care and how they construct well-being?

4. How do well-being and quality of life of male and female carers of people with dementia of different ages change over time?
5. What factors influence the time commitment of different tasks by men and women of different ages caring for a relative with dementia?

1.6 Outlining the thesis and significant contributions

The research questions in this thesis are addressed in eight chapters. First, in Chapter 2 a literature review using a systematic approach will investigate the question 'How is carer well-being and quality of life conceptualised and measured in the literature?' The review will focus on measures used to estimate the well-being and quality of life of carers in previous research. This analysis will also look at variables considered to influence carers' well-being and quality of life. Finally, a conceptual framework will be developed to inform analyses to be conducted as part of this thesis.

Chapter 3 will focus on the methods employed in this thesis. The chapter will outline the relevance of mixed methods research in the context of the topic of this thesis. In this chapter the three datasets used in this thesis will be described and their limitations will be presented. The chapter will also provide information on the qualitative interviews conducted as part of this thesis. In addition, detailed information on the methods of quantitative and qualitative analysis used in this thesis as well as their limitations will be presented.

Chapter 4 focuses on descriptive similarities and differences between the datasets used in this thesis and population-representative data on unpaid carers in England. It is therefore responding to the research question 'Are the characteristics of unpaid carers in England comparable to unpaid carers of people with dementia?' I will employ three datasets: from the START, SHIELD-CSP-RYCT and MODEM studies. For the comparison data from the English Longitudinal Study of Ageing (Wave VI) and the population Census (2011) will be used.

Chapter 5 presents analysis of qualitative interviews with 25 carers investigating the question 'Are there differences in how husbands, wives, daughters and sons of people with dementia experience the provision of care and how they construct well-being?' The data will be analysed using thematic analysis and the results will be discussed in light of the conceptual framework developed from the literature review.

Chapter 6 will respond to the research question 'How do well-being and quality of life of male and female carers of people with dementia of different age change over time?' For this purpose, quantitative analysis of the three datasets MODEM, START

and SHIELD-CSP-RYCT will again be conducted, spanning the time period of one year. The analysis, in line with the overall thesis, will focus on family carers supporting relatives in the community. Variables reflecting the concepts of well-being and health-related quality of life, as outlined in Chapter 2 will be used as outcome variables. Independent variables will be chosen in light of the conceptual framework developed for this thesis.

Chapter 7 will investigate the time commitment of family carers, as it has been recognised that the often long hours committed to supporting a relative with dementia can influence people's well-being and quality of life (Joling et al., 2015; Chappell & Reid, 2002). This analysis investigates the question 'What factors influence the time commitment of different tasks by men and women of different age groups caring for a relative with dementia?' The data will be analysed using cross-sectional data from the MODEM cohort.

Finally, Chapter 8 will offer a discussion of the overall set of results in the thesis. The focus will be the presence or absence of differences between carer gender, age and relationship to their care-recipient to respond to the main research question 'Does the well-being and health-related quality of life of people providing unpaid care for people with dementia in the community vary by age and gender?' A conclusion will be offered.

Chapter 2

Context and Framework

The terms ‘well-being’ and ‘quality of life’ are used frequently in policy documents aiming to support people with dementia and their carers (Care Act, 2014; Department of Health, 2009). However, little can be found on how the concepts of ‘well-being’ and ‘quality of life’ are defined in the context of dementia care. The absence of clear definitions led to the research question: ‘How is carer well-being and quality of life conceptualised and measured in the literature?’ To respond to this question, this chapter firstly explores definitions of well-being and quality of life. Next, a literature review is presented, which used a systematic approach and focused on how the well-being and quality of life of carers of people with dementia is measured in the literature. Similarities and differences between the concepts in both quantitative and qualitative research are then analysed and discussed. Finally, a framework of variables found to influence carer well-being and quality of life is presented and discussed.

2.1 Definitions of carer well-being

Defining well-being is associated with a number of difficulties. First, historically two distinct conceptual strands of well-being exist. One is ‘hedonic’, the other ‘eudaimonic’ well-being. While hedonic well-being focuses on well-being in relation to happiness as ‘pleasure attainment and pain avoidance’ (Ryan & Deci, 2001, p.141), eudaimonic well-being understands ‘well-being as distinct from happiness’ (Ryan & Deci, 2001, p.145). Eudaimonic well-being follows Aristotle’s thinking, in arguing that well-being (vivere bene) is not necessarily the fulfilment of momentary desires, but instead the realisation of desires ‘conducive to human growth’ (Fromm, 1981: xxvi). Hedonic well-being, on the other hand, focuses on three interrelated components: life satisfaction, pleasant affect and unpleasant affect. Hedonic well-being is therefore more closely linked to what is understood as happiness (Diener & Suh, 1997, p.200; Ryan & Deci, 2001, p.144). Even though both approaches have been recognised as substantive and multi-dimensional, it is important to reflect on these distinct concepts as they will result in different measures of well-being. This could mean that a measure focusing on the concept of hedonic well-being may ask respondents how happy and satisfied they feel with their life, while another measure based on eudaimonic concepts would investigate how meaningful people rate experiences in their life to be. Both questions could exist next to each other, however, their outcome and interpretation may differ.

Furthermore, well-being in the literature is often differentiated into subjective, personal, psychological and objective well-being (Ask et al., 2014; ONS, 2016b; Charlesworth et al., 2008; Fauth et al., 2012; Gaugler et al., 2003; Harwood et al., 2000; Rapp & Chao, 2000; Ryff, 2014; Williams et al., 2010). Subjective well-being emphasises life satisfaction, which mostly favours hedonic components such as positive emotions, but also contains of eudaimonic concepts such as meaningfulness of life (Angner, 2010). Personal and psychological well-being, due to their conceptual similarities here will be grouped with subjective well-being. Personal well-being, for instance, is used by the ONS in England to better understand how adults in the UK feel about their lives. In the ONS measure four questions are used to elicit people's responses ('Overall, how satisfied are you with your life nowadays?', 'Overall, to what extent do you feel the things you do in your life are worthwhile?', 'Overall, how happy did you feel yesterday?', 'Overall, how anxious did you feel yesterday?') (ONS, 2016b). The first, third and fourth questions reflect hedonic well-being, while the second question elicits eudaimonic well-being. Hence, the measure, as observed in the definition of subjective well-being reflects an emphasis on hedonism.

Similarly, the discourse on psychological well-being traditionally focused on the previously introduced concepts of positive and negative affect and life satisfaction, reflecting predominantly concepts of hedonic well-being (Maslow, 1968; Ryff, 1989; Diener & Suh, 1997). Ryff (1989, p.1070), however, pointed out that existing literature was not 'strongly theory guided'. Based on a critique of the reflections of theoretical underpinnings, including perspectives such as 'Maslows's conception of self-actualization', Ryff developed a model of well-being that consists of six core dimensions, namely: purpose in life, environmental mastery, positive relationships, personal growth, autonomy and self-acceptance (Ryff, 1989, p.1070; Ryff, 2014). These dimensions reflect the importance of both hedonic and eudaimonic components to the concept of psychological well-being. Objective well-being, in contrast, focuses on concepts deemed necessary to maintain a healthy society, such as physical health, education and human rights (Department of Health, 2014, p.6). This thesis focuses mainly on the concepts of subjective, personal and psychological well-being.

A care-related definition of subjective well-being from the British Government states that:

'"Wellbeing" is personal dignity (including treatment of the individual with respect), physical and mental health and emotional well-being, protection from abuse and neglect, control by the individual over day-to-day life (including over care and support

provided and the way it is provided), participation in work, education, training or recreation, social and economic wellbeing, domestic, family and personal, suitability of living accommodation, and the individual's contribution to society' (Care Act, 2014, pp.1-2).

The OECD Guidelines on measuring subjective well-being in comparison define the concept more widely as '*Good mental states, including all of the various evaluations, positive and negative, that people make of their lives and the affective reactions of people to their experiences'.* This definition, in part, reflects the influential report of the Commission on the Measurement of Economic Performance and Social Progress by Stiglitz, Sen and Fitoussi (2009) who described subjective well-being as a product of three aspects:

1) 'Cognitive evaluation of one's life'
2) 'Positive emotions (joy, pride)'
3) 'Negative emotions (pain, anger, worry)' (Stiglitz, Sen & Fitoussi, 2009) in OECD Guidelines

The authors noted that those three aspects should be measured separately to get a better understanding of people's quality of life.

This interpretation suggests that Stiglitz, Sen and Fitoussi view quality of life as part of 'well-being'. This is consistent with the literature, where well-being appears to be often viewed as partially overlapping or even interchangeable with the concept of quality of life (Snyder et al., 2015; Williams et al., 2010; Arango Lasprilla et al., 2009; Charlesworth et al., 2008; Tommis et al., 2007; Raina et al., 2004; Haley et al., 2004; Coen et al., 1999; Rapp et al., 1998; Camic, Williams, & Meeten, 2011; Takai et al., 2011; Duggleby et al., 2011). This has been highlighted, for instance, in the work of Shin and Johnson (1978:478) who understand well-being as 'a global assessment of a person's quality of life according to his own chosen criteria'. Dodge and colleagues (2012) compared the concept of well-being to the definition of quality of life by the World Health Organization (WHO), which states that people's 'perception of their position in life' is shaped by cultural concepts but also by their goals and expectations (Dodge et al., 2012, p.224). Satisfaction in life through the achievement of goals and expectations is inherently linked to the concept of eudaimonic well-being. A detailed analysis of conceptual differences and overlap in measures of quality of life and well-being used in the context of dementia care can be found in the literature review in Section 2.3.

As this thesis focuses on the well-being and quality of life of family carers of

people with dementia, the well-being definition of the Care Act 2014 appears overall to be appropriate. The definition focuses on subjective well-being by specifying emotional well-being and control over one's daily life. Furthermore, it encompasses relevant measures of objective well-being, such as people's social and economic well-being. Finally, the choice of a care-related definition of well-being set by the English government enables the analysis of dementia care-related policies in light of the official description of well-being.

2.2 Definitions of quality of life

Similarly to concepts of well-being, quality of life can be defined in different ways (Galloway et al., 2006, p.9). The WHO, for instance, defines quality of life as: *'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment'* (WHO, 1997: 1).

In this definition, quality of life encompasses a number of different concepts, such as people's independence, their ability to engage in personal relationships and the quality thereof. It also includes the ability to have personal opinions and beliefs as well as recognition of the environment in which people live. In this general definition, it has been recognised that aspects such as a person's beliefs, their level of independence, their relationships to other people and their environment can affect a person's well-being as much as their physical and mental health status.

In the context of health and social care, quality of life is frequently equated with the concept of health-related quality of life, which primarily focuses on physical and mental health. The Centers of Disease Control and Prevention (CDC) explain the difference between general quality of life and health-related quality of life by showing that health, while being an important domain of overall quality of life, co-exists with domains such as 'jobs, housing, schools, the neighbourhood […] aspects of culture, values and spirituality'. The concept of health-related quality of life according to the CDC instead focuses particularly on self-reported chronic diseases and related risk factors (CDC, 2016). NICE in England and Wales, on the other hand, uses a broader definition. Here, health-related quality of life is defined as 'a combination of a person's physical, mental and social well-being; not merely the absence of disease' (NICE,

2017a). The WHO definition of quality of life, as quoted above, shows strong links with concepts of well-being explored earlier. One could argue that if a person experiences good quality of life there is also a likelihood of experiencing components of well-being, such as being happy and feeling fulfilled.

However, in the context of dementia care a closer focus on health-related quality of life may be justified as the link between the experience of physical and mental issues and the provision of dementia care have been highlighted (Ory et al., 1999; Vitaliano, Zhang & Scanlan, 2003; Pinquart & Sörensen, 2007; Larkin, Henwood & Milne, 2018). The NICE definition of health-related quality of life therefore is particularly suitable in this context, as family carers of people with dementia frequently also experience challenges in maintaining their social relations, as their daily life focuses around making sure that the person with dementia is safe and well (NICE, 2017a).

2.3 The application of well-being and quality of life of carers in the literature

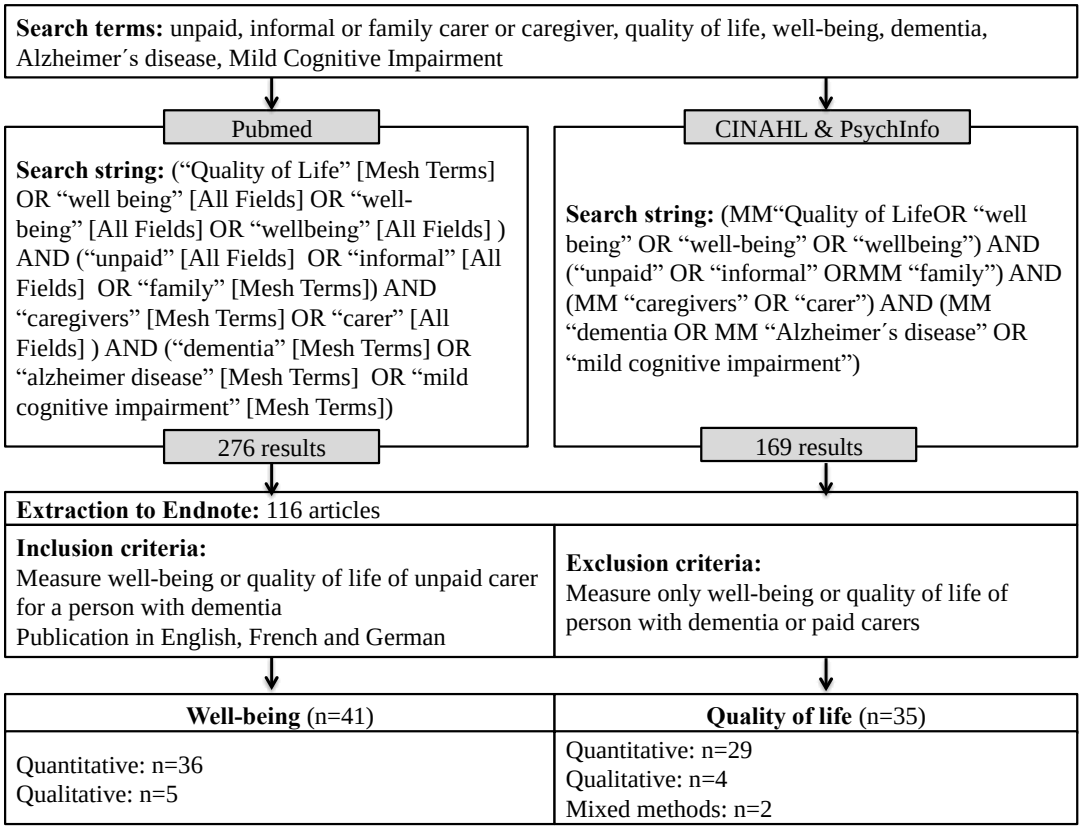
The variation in definitions of well-being and quality of life used, and particularly their frequent interchangeable application, can pose challenges to interpretation of research focusing on the well-being or quality of life of carers of people with dementia (Galloway et al., 2006, pp.9,33). Proponents of differentiation between and clarification of the concepts suggest that it is important to define what research aims to measure. Haas, for instance, recognised well-being as an aspect of quality of life, but emphasised the importance of clarity through defining what is being addressed (Haas, 1999; Galloway et al., 2006, p.34).

The following review of studies assessing well-being and quality of life of family carers of people with dementia seeks to shed light on how researchers in the field define and measure the concepts at hand. This review used a systematic approach to illustrate how well-being and quality of life of carers of people with dementia have been measured and conceptualised in the literature. The review was conducted searching the databases PubMed, PsycInfo and CINAHL for the terms ‘unpaid’ or ‘informal’ and ‘carer’ or ‘caregiver’ and ‘wellbeing’ or ‘well-being’ or ‘well being’ or ‘quality of life’ and ‘dementia’ or ‘Alzheimer’s Disease’ or ‘mild cognitive impairment’.

A total of 445 initial results were identified. Following the removal of duplicates and the screening of titles and abstracts, 116 articles remained. Articles met the inclusion criteria if papers stated that they measured the well-being or quality of life of unpaid carers for people with dementia. Furthermore, articles qualitatively exploring aspects of carer well-being or quality of life were included in the review. Articles that

did not focus on measuring well-being or articles published in languages other than English, German or French were excluded from the review, as illustrated in Figure 2.3.1. After obtaining full-texts and applying the outlined inclusion and exclusion criteria, 76 articles remained part of the review. Of these 41 articles focus on carer well-being and 35 articles report on carer quality of life. The majority of articles approach carer well-being or quality of life using a quantitative approach (n=66), nine articles use qualitative methods and two articles apply mixed methods.

Figure 2.3.1 Overview of the search strategy



Articles included in this review were conducted all around the world. Data measuring carer well-being was collected in Europe, Scandinavia, America, Asia and Australia. Most of these studies were based in the United States. Similarly, studies focusing on carer quality of life were developed in European, American, Asian and Australian countries. Most of the studies investigating carer quality of life came from European countries, followed by studies from the United States, Asia and Australia. An overview can be found in Table 2.3.1.

Table 2.3.1 Overview origin of studies included in review

	Carer QoL studies	*Carer Well-being studies*
Europe	• **The United Kingdom** (Orgeta et al., 2015; Camic, Williams & Meeten, 2011) • **Ireland** (Coen et al., 2001) • **The Netherlands** (Graff et al., 2007, Schölzel-Dorenbos et al., 2009) • **France** (Andrieu et al., 2007, Thomas et al., 2006) • **Spain** (Argimon et al., 2005, Argimon et al., 2004, Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006) • **Cyprus** (Papastavrou et al., 2014) • Data from a **eight European countries** (Bleijlevens et al., 2015) • **Norway** (Bruvik et al., 2012)	• **The United Kingdom** (Orgeta & Lo Sterzo, 2013, Charlesworth et al., 2008, Tommis et al., 2007; Quirk et al., 2009) • **Belgium** (Schoenmakers, Buntinx & DeLepeleire, 2010a) • **Ireland** (Coen et al., 1999)
Scandinavia		• **Finland** (Koivisto et al., 2015) • **Norway** (Ask et al., 2014) • **Sweden** (Holst & Edberg, 2011)
America	• **Brazil** (Santos et al., 2014, Inouye et al., 2009) • **Colombia** (Moreno et al., 2015, Arango-Lasprilla et al., 2010) • **The United States** (Gaugler et al., 2015, Vickrey et al., 2009, Belle et al., 2006, Bell, Araki & Neumann, 2001) • **Canada** (Bartfay & Bartfay, 2013, Duggleby et al., 2011)	• **Colombia** (Arango Lasprilla et al., 2009) • **United States** (Fauth, Femia & Zarit, 2016, Snyder et al., 2015, Kally et al., 2014, Williams et al., 2010, Roscoe et al., 2009, Fauth et al., 2012, Kwak et al., 2011, Gitlin et al., 2006, Pot et al., 2005, Haley et al., 2004, Gaugler et al., 2004, Gaugler et al., 2003, Coon et al., 2004, Rapp & Chao, 2000, Rapp et al., 1998, Spurlock, 2005, Harwood et al., 2001) • **Canada** (Raina et al., 2004, Chappell & Reid, 2002, Chiu, Wesson & Sadavoy, 2013)
Asia	• **Iran** (Abdollahpour et al., 2015) • **Taiwan** (Kuo et al., 2013; Kuo et al., 2014) • **Japan** (Takai et al., 2011) • **Russia** (Kolykhalov et al., 2011) • **China** (Zhang et al., 2014)	• **China** (Au et al., 2009; Cheung et al. 2015)
Australia	• **Australia** (Shuter, Beattie & Edwards, 2014, Logiudice et al., 1999)	• **Australia** (Chenoweth et al., 2016, McConaghy & Caltabiano, 2005)
		• **Israel** (Meller, 2001)

2.3.1 Carer well-being

In order to get an understanding of how well-being and quality of live have been conceptualised in the literature, first the outcome variables used in the articles were

identified. Next, the 26 different outcomes indicators identified from the quantitative literature were grouped into five main categories. These are: mental health, physical health, positively framed measures, negatively framed measures and external support. An overview can be found in Table 2.3.2.

Mental health measures were most frequently used to estimate carer well-being. The category mental health consists of the two sub-categories: depression and anxiety. Depression measures dominated in frequency with 24 studies using depression scales. The Center for Epidemiologic Studies Depression Scale (CES-D) developed by Radloff (1977) was used most commonly in 15 of 35 studies (Fauth, Femia & Zarit, 2016; Williams et al., 2010; Roscoe et al., 2009; Au et al., 2009; Kwak et al., 2011; Pot et al., 2005; Haley et al., 2004; Gaugler et al., 2004; Coon et al., 2004; Gaugler et al., 2003; Rapp et al., 1998; Raina et al., 2004; Schoenmakers, Buntinx & DeLepeleire, 2010a; Cheung et al., 2015; Harwood et al., 2000). Authors stated that the reason for using the CES-D measure was that it also included four positive measures of mental health ('I felt I was just as good as other people', 'I felt hopeful about the future', 'I was happy', 'I enjoyed life') (Radloff, 1977). Other standardised measures estimating carer depression included the Beck Depression Inventory (Schoenmakers, Buntinx & DeLepeleire, 2010a), the Geriatric Depression Scale (Chiu, Wesson & Sadavoy, 2013) or the Patient Health Questionnaire (PHQ-9) (Kally et al., 2014; Arango Lasprilla et al., 2009). The presence or absence of depression is understood to be an important determinant of carer well-being.

Anxiety and depression were measured jointly in eight studies (Ask et al., 2014; Fauth et al., 2012; Williams et al., 2010; Charlesworth et al., 2008; Tommis et al., 2007; Haley et al., 2004; Coon et al., 2004; Coen et al., 1999). Examples of these are the Hospital Anxiety and Depression Scale (HADS), the Short-Form 12 (SF-12) Questionnaire and the General Health Questionnaire (GHQ). The HADS was used as an outcome variable in two studies to estimate carer well-being (Ask et al., 2014; Charlesworth et al., 2008). This measure collects information on 14 items, half of them measuring the presence of depression and half of them the presence of anxiety. Similarly, the SF-12 was used as a primary outcome measure (Fauth et al., 2012; Tommis et al., 2007; McConaghy & Caltabiano, 2005; Chenoweth et al., 2016). Besides questions on respondents' emotions, this scale also collected information on the physical health state of the respondents.

Only once was anxiety used as a single mental health component (Snyder et al., 2015). A variety of standardised tools were found across studies to estimate the

presence, absence and degree of anxiety. Examples were the Spielberger State-Trait Anxiety Inventory (Williams et al., 2010; Haley et al., 2004; Coon et al., 2004), the Beck Anxiety Inventory (Snyder et al., 2015) or the CONOR Mental Distress Index (Ask et al., 2014). Similar to depression scales, anxiety scales collected information on the degree of symptoms of anxiety.

Carers' physical health was most frequently measured using the Short Form Questionnaire, either the 12- or 36-item version (Roscoe et al., 2009; Fauth et al., 2012; Tommis et al., 2007; McConaghy & Caltabiano, 2005; Chenoweth et al., 2016; Arango Lasprilla et al., 2009). Besides other standardised measures, such as the Patient Health Questionnaire (PHQ-9) (Arango Lasprilla et al., 2009; Kally et al., 2014) or the GHQ-30 (Coen et al., 1999), a number of studies made use of self-developed or adapted scales to determine carer physical health status (Snyder et al., 2015; Williams et al., 2010; Raina et al., 2004; Haley et al., 2004; Coon et al., 2004; Rapp et al., 1998). Physical health was used as an outcome measure in 13 out of 35 studies. This indicates that physical health was considered an important component of carer well-being.

Carer burden was also used as a proxy measure of well-being of carers of people with dementia, often in combination with other measures (see Table 2.4.3). Nine studies included carer burden as an outcome measure. Most commonly, burden was measured using the Zarit Burden Index (ZBI) (Chiu, Wesson & Sadavoy, 2013; Arango Lasprilla et al., 2009; Schoenmakers, Buntinx & DeLepeleire, 2010a; Raina et al., 2004; Chappell & Reid, 2002; Cheung et al., 2015). Other measures included the Lawton Subject Burden Instrument (Schoenmakers, Buntinx & DeLepeleire, 2010a), the Montgomery Borgatte Caregiver Burden Scale (Kwak et al., 2011), the Burden Interview Scale (Spurlock, 2005) or the use of a single item question (Holst & Edberg, 2011).

Followed in frequency was the measure of life satisfaction, with eight studies including this as a component of carer well-being. Standardised measures included the Life Satisfaction Index (Roscoe et al., 2009; Pinquart & Sörensen, 2004) or the Satisfaction with Life Scale (Arango Lasprilla et al., 2009; McConaghy & Caltabiano, 2005; Pinquart & Sörensen, 2004; Chappell & Reid, 2002). Single item questions on carer life satisfaction were also used (Ask et al., 2014; Holst & Edberg, 2011; Pinquart & Sörensen, 2004).

The diversity of scales, often employed in combination, used to measure carer well-being indicated that there was no single or dominant scale capturing all the many different aspects and definitions of well-being. One attempt was the Warwick-Edinburgh Mental Well-Being Scale, which was tested by Orgeta and Lo Sterzo (2013).

The scale aims to measure positive aspects of mental well-being encompassing both hedonic and eudaimonic concepts of well-being. Evidence of hedonic well-being can be found in statements such as 'I've been feeling good about myself' while statements falling under eudaimonic concepts are 'I've been feeling useful' or 'I've been interested in new things'. A second measure used to measure well-being through a single outcome scale was the Positive and Negative Affect Schedule (PANAS) (Fauth et al., 2012; Pot et al., 2005; Rapp & Chao, 2000; Charlesworth et al., 2008). This index used 20 adjectives describing positive or negative feelings. Respondents were asked to rate each adjective on a five-item scale. One study that used this measure focused particularly on carers' spiritual well-being (Spurlock, 2005).

The remaining categories used as measures of carer well-being can be separated into positively and negatively framed measures, as indicators of external support and other measures. Positively framed outcome measures include financial resources, quality of life, mastery, self-efficiency and self-esteem, coping, competence, positive aspects of caring, identity discrepancy, life satisfaction, well-being scales and social participation. In addition, a number of negatively framed measures were identified as informative of carer well-being. These include carer burden, anger, hostility, management of behavioural problems or hassles, captivity, overload, stress and family conflict, loneliness and substance use. The importance of social networks on carer well-being has been recognised and measured on few occasions. In this analysis, measures capturing social networks fell into the category 'support and service use'. This category was understood as containing factors informing carer well-being rather than being proxy indicators and have only been used as secondary outcome measures in two studies (Kwak et al., 2011; Pot et al., 2005).

Table 2.3.2 Overview of studies quantitatively measuring carer well-being

	Mental Health		PH	Positively framed measures											Negatively framed measures										Service	
	Depression	Anxiety	Physical health	Financial resources	Quality of life	Mastery	Self-efficacy/ self-esteem	Coping/Meaning	Competence	Positive aspects of caring	Identity discrepancy	Life Satisfaction	Well-being scale	Social participation	Burden	Anger	Hostility	Management of Behavioural problems/ Hassles	Captivity	Overload	Stress	Loneliness	Substance use	Family conflict	Support	Service use
Koivisto et al., 2015	X				X																X					
Fauth, Femia & Zarit, 2016	X																		X	X						
Chenoweth et al., 2016							X																			
Snyder et al., 2015		X	X																							
Cheung et al., 2015	X									X					X			X								
Kally et al., 2014	X					X		X	X									X								
Ask et al., 2014	X	X										X														
Orgeta & Lo Sterzo, 2013													X													
Chiu, Wesson & Sadavoy, 2013	X					X		X	X						X				X	X						
Quirk et al., 2009													X													
Fauth et al., 2012	X	X	X										X													
Kwak et al., 2011	X										X				X											X
Holst & Edberg, 2011												X			X											
Williams et al., 2010	X	X	X													X	X				X					
Schoenmakers, Buntinx & DeLepeleire, 2010a	X														X											
Roscoe et al., 2009	X		X									X	X									X				
Arango Lasprilla et al., 2009	X		X									X			X										X	
Au et al., 2009	X																									
Charlesworth et al., 2008	X	X	X																							
Tommis et al., 2007	X	X	X																							

	Mental Health		PH	Positively framed measures											Negatively framed measures										Service	
	Depression	Anxiety	Physical health	Financial resources	Quality of life	Mastery	Self-efficacy/ self-esteem	Coping/Meaning	Competence	Positive aspects of caring	Identity discrepancy	Life Satisfaction	Well-being scale	Social participation	Burden	Anger	Hostility	Management of Behavioural problems/ Hassles	Captivity	Overload	Stress	Loneliness	Substance use	Family conflict	Support	Service use
Gitlin et al., 2006													X													
Spurlock, 2005													X		X											
Pot et al., 2005	X												X							X	X			X		
McConaghy & Caltabiano, 2005												X														
Raina et al., 2004	X		X												X											
Pinquart & Sörensen, 2004												X														
Haley et al., 2004	X	X	X																							
Gaugler et al., 2004	X															X					X					
Coon et al., 2004	X	X	X										X										X			
Gaugler et al., 2003	X															X		X			X					
Chappell & Reid, 2002						X						X			X											
Meller, 2001			X	X								X		X							X					
Rapp & Chao, 2000													X													
Harwood et al., 2001	X																									
Coen et al., 1999	X	X	X		X																					
Rapp et al., 1998	X		X		X				X																	
Total	24	9	13	1	3	3	1	2	3	1	1	8	9	1	9	3	1	3	2	3	6	1	1	1	1	1

2.3.2 Quality of life

The comparison of outcome measures used to estimate carers' quality of life led to a very different picture (see Table 2.3.3). A number of standardised scales measuring quality of life in the context of dementia care were identified. Four studies used the Quality of Life in Alzheimer's Disease (QoL-AD), a measure specifically designed to collect quality of life of people with dementia, which can also be used for carers of people with dementia (Orgeta et al., 2015; Papastavrou et al., 2014; Bartfay & Bartfay, 2013; Bruvik et al., 2012). This scale captures respondents' feelings of aspects such as their mood, physical health, energy, family life, marriage, friends, self as a whole, ability to do chores, ability to have fun, living situation, life as a whole, memory and financial situation (Logsdon et al., 2002).

Other common measures included the EQ-5D (Moreno et al., 2015; Bleijlevens et al., 2015; Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006) and the quality of life measure developed by the WHO (Camic, Williams & Meeten, 2011; Takai et al., 2011; Duggleby et al., 2011). The SF-36, previously noted as a proxy index of carer well-being by measuring carer mental and physical health, was also repeatedly used as a quality of life proxy measure (Kuo et al., 2013; Arango-Lasprilla et al., 2010; Argimon et al., 2004; Moreno et al., 2015; Zhang et al., 2014; Kuo et al., 2014; Argimon et al., 2005).

Even though carer quality of life was commonly measured using a single index, there was some variety to the tools available. The column 'other' in Table 2.3.3 illustrates this. Furthermore, it was interesting to note that out of 31 studies measuring carer quality of life, only one study used several scales. Belle and colleagues (2006) defined carer quality of life as a composite of carer burden, self-care and depression.

Table 2.3.3 Overview of studies quantitatively measuring carer quality of life

	QoL-AD	EQ-5D	SF-36	WHO QoL	Other	Psychological aspect of quality of life	Burden	Self care	Depression
Orgeta et al., 2015	X								
Moreno et al., 2015			X						
Gaugler et al., 2015					Cantril ladder				
Bleijlevens et al., 2015		X				GHQ-12			
Abdollahpour et al., 2015					Single question				
Zhang et al., 2014			X						
Santos et al., 2014					QoL				
Papastavrou et al., 2014	X								
Kuo, et al., 2014			X						X
Kuo et al., 2013			X						
Camic, Williams & Meeten, 2011				X					
Bartfay & Bartfay, 2013	X								
Bruvik et al., 2012	X								
Takai et al., 2011				X					
Kolykhalov et al., 2011					Anxiety				X
Duggleby et al., 2011				X					
Arango-Lasprilla et al., 2010			X						
Vickrey et al., 2009					Caregiving assistance, carer feelings				
Schölzel-Dorenbos et al., 2009					SEIQoL				
Inouye et al., 2009					CQofL-AD				
Graff et al., 2007					Dqol				
Andrieu et al., 2007					COOP/WONCA				
Thomas et al., 2006					Scale pixel study				
Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006		X							
Belle et al., 2006					Social support, problem behaviours		X	X	X
Argimon et al., 2005			X						
Argimon et al., 2004			X						
Coen et al., 2001					SEIQoL				
Bell, Araki & Neumann, 2001					HUI2				
Logiudice et al., 1999					FLP				
Total	4	2	7	3	14	1	1	1	3

Components of quality of life measures

Since in the majority of studies investigating quality of life this construct was measured using standardised measures, it was considered important to look at their components in order to understand the underlying aspects considered as making up quality of life. For this purpose, the four measures most commonly used in this review to assess quality of life of carers of people with dementia were investigated. Table 2.3.4 divides the components of the four measures QoL-AD, EQ-5D, SF-36 and the WHO QoL Bref into seven categories. These are: mental health, physical health, ability to engage in an active life, relationships, environment, finances and other.

Mental health components were measured in all four scales. While the EQ-5D focused on the presence of anxiety and depression, the other three measures used a number of indicators. QoL-AD, SF-36 and the WHO QoL Bref, for instance, inquired about respondents' mood. Respondents' energy levels were collected in the QoL-AD and SF-36. The WHO measure delved deeper into mental health by eliciting information on the frequency of which people 'have negative feelings such as blue mood, despair, anxiety, depression' (WHO QoL Bref). Similarly, a range of indicators of depression and anxiety were collected in the SF-36.

Components of physical health were measured using a range of indicators. The QoL-AD only posed one question directly focusing on respondents' physical health: 'First of all, how do you feel about your physical health? Would you say it's poor, fair, good, or excellent?' The EQ-5D, on the other hand, collected three different indicators by questioning interviewees on mobility, pain and discomfort and the ability to wash and dress themselves. The WHO QoL Bref and the SF-36 collected information on the presence of pain or treatment for physical ailments as well as respondents' mobility. The SF-36 additionally inquired about people's ability to perform a range of activities, such as participating in vigorous activity or climbing several flights of stairs.

The third category labelled 'ability to engage in an active life' contained indicators that go beyond either mental or physical health indicators. Examples are the ability to do chores, to do things for fun or to participate in usual activities. All of these required people to have capacity in physical and mental health. While some people may have had the physical capacity, poor mental health may have prevented them from engaging in activities. On the other hand, if physical ability was limited this also could have stopped people from performing a range of activities. These components were measured in all four scales.

Other examples used in all four measures were questions on carers' general health. These required respondents to report on how they generally felt about themselves, how they rated their overall health or how they rated their health in comparison to other people in their environment. The SF-36 additionally estimated people's abilities in engaging in social activities due to mental or physical impairments. The measure developed by the WHO included a number of components not collected in the three other scales. These were ratings on overall quality of life, the degree to which people enjoyed their lives, were satisfied with themselves, lived a meaningful life, got decent sleep, had a good sex life, were able to concentrate, got opportunities for leisure and had capacity to work.

Relationships with family and friends made up the fourth category. This kind of data was only gathered in the QoL-AD and the WHO QoL Bref. The QoL-AD measured respondents' feelings towards relationships with their partner, family and friends. The WHO measure also collected information on people's personal relationships. The scale additionally gathered data on people's support network and the degree to which this support was deemed appropriate.

The remaining two categories ('environment' and 'finances') were only collected in the QoL-AD and WHO QoL measures. While the QoL-AD just inquired about respondents' living situation the WHO measure additionally captured information on the perceived safety of people, a rating of their physical environment, access to necessary information, transportation and health services. Both measures inquired about interviewees' financial situation by asking how the respondents felt about their current financial situation. Only one aspect of the QoL-AD, the measure initially developed for people with dementia, fell into the category 'other'. This was a question about respondents' perception of their memory.

Table 2.3.4 Overview components of quality of life measure

	QoL-AD	**EQ-5D**	**SF-36**	**WHO QoL Bref**
Mental health	Mood Energy	Anxiety/Depression (mental)	Limitations due to emotional problems Mood (mental) Energy (mental)	Mental health Energy
Physical health	Physical health	Self care (washing/dressing) Mobility (physical) Pain/discomfort (physical)	Activities (physical) Limitations due to physical health Bodily pain (physical health)	Pain, treatment (physical) Mobility
Ability to engage in an active life	Ability to do chores Feel about yourself Ability to do things for fun Life as a whole	Usual activities (physical and mental) Overall health	General health Limitation Activities (physical) Limitation Activities (emotional) Comparative health	Quality of life General health Life-satisfaction Meaningful life Sleep Sex life Abilities of daily living Enjoy life Opportunity for leisure Work capacity Concentration
Relationships	Family relations Marriage Relationship to friends			Personal relationship Support from others Support
Environment	Living situation			Safety Physical environment Information Living place Transportation Access to health services
Finances	Money/finances			Money
Other	Memory			

2.3.3 Similarities and differences between quality of life and well-being measures

After having investigated the different components of the four most frequent measures used to estimate quality of life of carers of people with dementia, in this next section I will draw on similarities and differences between aspects measured under the concepts 'well-being' and the components of the four 'quality of life' measures QoL-AD, EQ-5D, SF-36 and WHO QoL Bref.

A key component of both quality of life and well-being is the understanding of people's mental health. As outlined above, 24 out of 36 studies in this review used measures of mental health, such as depression and anxiety scales, as primary outcome indicators for carers' well-being. Similarly, all four quality of life measures investigated included components on anxiety, depression, mood and energy. However, some of the instruments used to measure well-being, such as the CES-D, included more aspects of mental health than any of the four quality of life measures (Radloff, 1977).

Indicators of carers' physical health states have also been collected in all four quality of life studies, as well as in 13 out of 36 well-being studies. This shows that while physical health is a key component in the concept of quality of life, there appears to be disagreement with respect to its association with the concept of well-being. From the studies available it remained unclear whether the decision to exclude physical health components in over half of the well-being studies was deliberate or whether this was in part determined by the availability of data.

The category 'ability to engage in active life' showed a number of aspects for each of the four quality of life measures. The overall emphasis appeared to be on people's physical and mental ability to participate in everyday life. This was not a focus in the well-being measures. However, one study included social participation as an outcome measure (Meller, 2001). In this group fell also a question on quality of life. It was included in the WHO measure. Interestingly, quality of life was also measured in three of the well-being studies (Koivisto et al., 2015; Coen et al., 1999; Rapp et al., 1998). The inclusion of quality of life as part of well-being links back to the earlier conceptual discussion highlighted by the Stiglitz, Sen and Fetussi paper (2009) (see Section 2.1). The lack of conceptual clarity with respect to the relationship between well-being and quality of life becomes apparent in the inclusion of life-satisfaction in the WHO quality of life measure. Life satisfaction, as discussed above, reflects the concept of hedonic well-being and was also captured in eight well-being studies (Ask et al., 2014; Holst & Edberg, 2011; Roscoe et al., 2009; Arango Lasprilla et al., 2009;

McConaghy & Caltabiano, 2005; Pinquart & Sörensen, 2004; Chappell & Reid, 2002; Meller, 2001).

In the analysis of components of quality of life measures, the categories, 'relationships', 'environment', 'finances' and 'other' were outlined. These components were only considered in the QoL-AD and the the WHO QoL measure. Comparing these components to outcomes used to estimate carer well-being (see Table 2.3.2) showed only limited overlap. Aspects of the category 'relationship' were only considered as outcome measures in two well-being studies. One study investigated family conflict (Pot et al., 2005), while another focused on support (Arango Lasprilla et al., 2009). None of the outcome measures of quality of life measures included the carer's environment. Financial resources, as covered in the category 'other' in the quality of life measure comparison was only part of one well-being study (Meller, 2001).

Overall, components of well-being studies appeared to place a greater focus on emotional experiences formulated in both positive and negative ways. Examples were the measure of feelings of mastery, self-efficacy or self-esteem, competence but also those of burden, anger, overload, loneliness and stress (see Table 23.3). In the studies focusing on quality of life, these components were largely absorbed in the mental health components of the questionnaires.

This comparison shows that while quality of life measures bring together a number of mostly objectively measurable aspects, studies employing the concept of well-being tend to focus on subjective, personal experience of care. The WHO quality of life measure appears to fit most closely with outcome measures observed from well-being studies.

2.3.4 Eudaimonic and hedonic concepts in measures of well-being

As the analysis of components included in the four most frequently used quality of life measures gave insights on the conceptualisation of the concept of quality of life, a closer look at components of well-being outcome measures might help to shed some light on the conceptual association with hedonic and eudaimonic well-being.

Concepts of eudaimonic and hedonic well-being were found in well-being measures, such as the WEMBS or the PANAS. Examples of questions measuring the concept of eudaimonia were rating the applicability of adjectives such as 'enthusiastic' or 'excited' used in the PANAS (Fauth et al., 2012; Pot et al., 2005; Rapp and Chao, 2000; Charlesworth et al., 2008). Other more clearly phrased statements such as 'I've been feeling good about myself' or 'I've been feeling cheerful' were used in the WEMWBS (Orgeta & Lo Sterzo, 2013). Both these measures also included components

fitting the concept of hedonic well-being. Positively and negatively framed examples from the PANAS were the adjectives ‘determined’ and ‘guilty’. In the WEMWBS the statement ‘I’ve been feeling useful’ was a good example of hedonic well-being. Life satisfaction scales also pick up on these concepts of well-being. The life satisfaction index, for instance, included statements such as ‘I am just as happy as when I was younger’ (hedonic) or ‘the things I do are as interesting to me as they ever were’ (eudaimonic) (Franchignoni et al., 1999). Table 2.3.2 shows that 17 studies included in this review either used a measure of life satisfaction or well-being.

A number of other measures used as positively or negatively framed outcome measures in this study also loosely fit with the concepts of hedonic or eudaimonic well-being. Examples of these categories are mastery, self-efficacy, coping or competence but also burden, hostility, hassle, overload or stress. While these categories are likely to influence well-being, well-being may not be their ultimate outcome. In six studies these categories were used jointly with measures of life satisfaction or well-being (Arango Lasprilla et al., 2009; Holst & Edberg, 2011; Spurlock, 2005; Pot et al., 2005; Chappell & Reid, 2002; Cheung et al., 2015). However, in 12 studies these indicators were only used together with measures of mental and physical health (Koivisto et al., 2015; Fauth, Femia & Zarit, 2016; Chenoweth et al., 2016; Cheung et al., 2015; Kally et al., 2014; Chiu, Wesson & Sadavoy, 2013; Kwak et al., 2011; Williams et al., 2010; Schoenmakers, Buntinx & DeLepeleire, 2010a; Raina et al., 2004; Gaugler et al., 2004; Chappell & Reid, 2002; Rapp et al., 1998). This suggests that there may be limited conceptual agreement on the collection of well-being indicators of carers of people with dementia.

This notion of limited conceptual agreement was also reflected in the limited use of definitions (n=6) of well-being (Fauth et al., 2012; Schoenmakers, Buntinx & DeLepeleire, 2010a; Pinquart & Sörensen, 2004; Haley et al., 2004; Chappell & Reid, 2002; Rapp & Chao, 2000). It was noticeable, however, that a number of authors used frameworks, such as Pearlin’s stress-process model when studying carer well-being (e.g. used in Fauth, Femia & Zarit, 2016; Snyder et al., 2015; Roscoe et al., 2009; Pot et al., 2005; Raina et al., 2004; Gaugler et al., 2003).

Pearlin and colleagues developed the stress process model around 1980. The model seeks to explain the sources, mediators and manifestations of social stress and its influence on depression. Social stress is understood to develop under circumstances of stressful discrete events or continuous problems. A direct link between stress, physiological and psychological consequences was established through the concept of

equilibrium. This means that events can cause disequilibrium in the organism until the person has adjusted to this change. Stress is experienced until equilibrium is re-established. The number of events, as well as their magnitude, influence the degree of disequilibrium experienced and hence the time and energy needed for adjustment. The experience of stress therefore is negatively linked to the concepts of mastery and self-esteem. Mastery is defined as the degree to which individuals feel in control of their lives. Self-esteem is understood as judgement of one's self-worth. Pearlin and colleagues also identified two mediating resources that might influence the degree to which stress is experienced. The first mediator is social support. Access to social support, such as from individuals, groups or organisation supporting the individual during stressful episodes can reduce the level of stress experienced and reduce potential physical and psychological consequences. The authors emphasised the nature of a support system. The sheer presence of a social network, however, does not necessarily equate to social support. The second resource is coping. Coping refers to the way people concerned deal with stress. People presenting the ability to modify the situation in their interest, to reduce the meaning of the stressor and to manage stress symptoms are likely to reduce the level of stress experienced (Pearlin et al., 1981; Pearlin et al., 1990).

The stress process model picks up on important components encompassed in the concept of personal well-being. Physical, mental health and emotional well-being can be affected during periods of extended and/or severe stress. The link between provision of dementia care to a family member and the experience of stress has been well established in the literature (Orgeta & Lo Sterzo, 2013; Pinquart & Sörensen, 2004). In addition, the importance of social resources and coping mechanisms, particularly on carers' mental health was proven multiple times (e.g.Snyder et al., 2015; Orgeta & Lo Sterzo, 2013). It is therefore understandable that many authors borrow the concept for the purpose of measuring carer well-being. However, this raises an important conceptual question. If the presence and degree of stressors is causing depression, does this equate to the absence of stressors and depression meaning well-being? I would argue that while concepts of hedonic and eudaimonic well-being are affected by stress and depression as one of its outcomes, the absence of stress cannot be equalised with well-being. Despite stressful experience in the provision of care many carers find meaning or eudaimonic well-being in their care activity. Furthermore, while excessive stress and the experience of depression are clearly linked to a reduction in happiness (hedonic well-being), many carers emphasise the importance of caring for a relative with dementia and report to derive happiness from doing so (Jones, Tudor Edwards &

Hounesome, 2014). The stress-process model, while being a complex and helpful model should not be made to a 'well-being model' as it neither fulfils the philosophical concepts nor have Pearlin and colleagues (1990) aspired to conceptualise well-being.

2.3.5 Qualitative studies

Only few qualitative studies that aimed to better understand aspects of carer well-being and quality of life were identified in the literature review. Five studies explored carer well-being. Chenoweth and colleagues (2016) explored how a programme developed to improve self-efficacy affected the health and well-being of carers in Australia. A second study explored the implications of being a re-married carer on well-being (Wexler Sherman, 2012). The third study focused on the effects of a night-time monitor on the well-being of carers of people with dementia who wander at night (Spring, Rowe, & Kelly, 2009). Hasselkus and Murray (2007) explored the impact of everyday experiences on carer well-being in the United States. Finally, a fifth study analysed psychological well-being (IKIGAI) in the Japanese context (Yamamoto-Mitani & Wallhagen, 2002).

Quality of life of carers of people with dementia using a qualitative or mixed methods approach was explored in six studies. Shuter, Beattie and Edwards (2014) explored how grief can affect carers' quality of life. A second study investigated whether capability-based instruments could provide insights into quality of life of carers (Jones, Tudor Edwards & Hounesome, 2014). The third study used mixed methods to evaluate the impact of a singing group on the quality of life of people with dementia and their carers (Camic, Williams & Meeten, 2011). The fourth study used mixed methods to get a better understanding of aspects influencing carers' quality of life (Duggleby et al., 2011). Finally, Vellone and colleagues (2008), similarly to Duggleby and others (2011), explored factors affecting carers' quality of life.

In all 11 studies carers shared insights in how the provision of dementia care affected people's well-being or quality of life. In the following I will briefly outline 15 themes that emerged from the literature in either quality of life or well-being related studies. The themes are: worry, guilt, stress/burden and conflict, grief, family support, paid support, the care-recipient, the carer care-recipient dyad, the illness, finances, carer health and carer self, personal space, recognition, belonging and social connections.

<u>Worries, stress, burden, guilt and grief</u>

In both well-being and quality of life studies, carers expressed experiencing numerous worries. The unpredictability of the progression of the illness was discussed.

It was understood that unpredictability of the care situation caused insecurity in terms of anticipation of needs and the ability of managing those in the future (Spring, Rowe, & Kelly, 2009; Vellone et al., 2008). Other worries included the safety of care-recipients, particularly at night, worries about whether the care-recipient may cause a publicly embarrassing scene due to inappropriate behaviour (Spring, Rowe, & Kelly, 2009), but also the worry of carers that their expressed need for support may generate burden for others (Jones, Tudor Edwards & Hounesome, 2014).

Similarly, feelings of guilt were expressed in studies focusing on carer well-being and quality of life. Carer guilt was mostly related to situations where carers decided to prioritise their own needs. This could mean leaving the care-recipient with another carer or in an institutional care setting (Chenoweth et al., 2016; Jones, Tudor Edwards & Hounesome, 2014). Related to guilt is the theme of stress, burden and conflict which was expressed when carers felt as if they were consumed by their care responsibility without receiving support perceived as appropriate or when members of the family overtly criticised the care provided (Wexler Sherman, 2012; Duggleby et al., 2011). The study by Jones, Tudor Edwards and Hounesome (2014) concluded that the level of burden increases with the proximity in kinship. Related to this point, Wexler Sherman (2012), whose work focuses on re-married carers, found that re-married partners can experience particularly challenging situations with their partner's first family.

Shuter, Beattie and Edwards (2014) investigated the experience of carer grief. Carers expressed the feeling of losing their care-recipient twice, once through the illness and a second time when the person passed away. One carer felt that support that was offered after the care-recipient had passed away would have been much more helpful while the care-recipient was still alive (Shuter, Beattie & Edwards, 2014).

Instrumental and emotional support from family and paid carers

The frequent experience of worries, stress, burden, guilt and grief highlights the importance of emotional and instrumental support from family members. This was recognised as important in well-being and quality of life studies. Support from family and friends was mentioned as important, and when such support is provided carers expressed their appreciation for it (Jones, Tudor Edwards & Hounesome, 2014; Duggleby et al., 2011; Wexler Sherman, 2012). On the other hand; Wexler Sherman, (2012) found that when family was unsupportive or in denial of the illness this could lead to feelings of isolation.

Interaction with and support from paid carers was discussed as an important aspect in both well-being and quality of life papers. Some carers struggled with passing

on responsibility for the care-recipient (Chenoweth et al., 2016). Those engaging with paid services either found it to be of great help or were deeply disappointed. If paid carers were to be perceived as helpful, supportive and acting in the interest of the care-recipient praise for support and advice was given (Shuter, Beattie & Edwards, 2014; Duggleby et al., 2011; Hasselkus & Murray, 2007). However, when paid carers were perceived to be lacking respect for the care-recipient and/or understanding for the situation carers regretted the decision to involve third party support (Hasselkus & Murray, 2007; Shuter, Beattie & Edwards, 2014).

The care-recipient, the dyad and the illness

Of great importance, in both well-being and quality of life studies, was the care-recipient. Carers often expressed their own well-being or quality of life by referring to how the care-recipient was doing. Enabling the care-recipient's independence, supporting the participation in activities and maintaining the relationship between carer and care-recipients were of great importance to carers (Chenoweth et al., 2016; Hasselkus & Murray, 2007; Camic, Williams & Meeten, 2011; Vellone et al., 2008). The importance of the relationship was often expressed through emphasising the dyadic experience. Carers highly valued moments when the person they supported showed enjoyment of an activity, such as watching a movie or enjoying their favourite food or expressing their gratitude and appreciation for the carer (Hasselkus & Murray, 2007; Jones, Tudor Edwards & Hounesome, 2014).

Experiencing the progression of dementia in the care-recipient could make carers feel frustrated. While some carers accepted the negative impact dementia had on both their own and their care-recipient's life, carers emphasised the initial difficulty of getting a diagnosis, frustration regarding limited or scattered information and feeling overwhelmed by the initial attention given post diagnosis (Chenoweth et al., 2016). At the same time, carers, and particularly those caring for people exhibiting challenging behaviour, emphasised the importance of continuous learning for a better understanding (Chenoweth et al., 2016; Jones, Tudor Edwards & Hounesome, 2014).

The carers' health and self, need for personal space, social connections, belonging and recognition

Carers also revealed a number of personal components to their well-being and quality of life. Carers in two studies reported their goal to be to better look after themselves and to grow as a person (Chenoweth et al., 2016; Duggleby et al., 2011). Other carers reported health problems due to the stress experienced from providing

dementia care. Negative outcomes reported included weight gain, need for antidepressants, physical health problems, lack of sleep and energy as well as mood changes (Wexler Sherman, 2012; Spring, Rowe, & Kelly, 2009).

Carers in both well-being and quality of life studies expressed the need for personal space, social connections, belonging and recognition for the support and care they provide. Looking after a relative with dementia was experienced by some carers as an occupation and/or biographical disruption, a time in people's life during which the changing needs of another person overrode personal choice (Hasselkus & Murray, 2007). The opportunity to get away from the caring responsibility and to regain moments of personal space was valued by carers, whereas those who did not get the opportunity expressed frustration (Wexler Sherman, 2012; Spring, Rowe, & Kelly, 2009; Jones, Tudor Edwards & Hounesome, 2014; Vellone et al., 2008; Chenoweth et al., 2016). A sense of belonging was also identified as important by carers. The study by Camic, Williams and Meeten (2011) showed that even shared participation in a singing group could provide carers with a sense of belonging and security. Carers felt that they were not alone in their experience and others understood their situation and worries. Recognition of the carer role was considered as important in both quality of life and well-being studies (Jones, Tudor Edwards & Hounesome, 2014; Hasselkus & Murray, 2007).

A distinct eudaimonic concept of well-being was discussed in the study by Yamamoto-Mitani and Wallhagen (2002). Here the authors emphasised that carers needed to find deep meaning and pride in their care role in order to overcome the challenges of dementia care. It was suggested that carers may apply techniques such as daydreaming or maintaining a philosophy (e.g. being a good Christian) to overcome times of strain. The study argued that if caring was valued highly enough, the loss of other aspects in life could be compensated for.

The comparison of topics raised and explored in qualitative studies focusing on carer quality of life and carer well-being showed a great overlap in content. The studies did not provide the theoretical background that allowed a distinction to be made between concepts of well-being and quality of life. Even more than in quantitative studies, the line was blurred between what is considered quality of life and what is understood to be well-being.

2.4 Discussion and summary

After having explored the different components of quantitative and qualitative studies focusing on the well-being and quality of life of carers of people with dementia and after having compared their similarities and differences, a rather blurred picture emerged.

Carer quality of life predominantly was assessed through standardised scales. Even though there was some variety in measures chosen, the comparison of the four most frequently used measures (QoL-AD, EQ-5D, SF-36 and WHO QoL) overwhelmingly showed conceptual overlap. All measures included components on carers' physical and mental health as well as on their ability to engage in an active life. Two of the measures, in addition, included questions on carers' relationships, their environment, finance and other aspects. Only the WHO quality of life measure stood out through its varied components, which among other things included a question on life satisfaction.

A greater variety of approaches could be found among studies aiming to measure carer well-being. Carer mental health (depression and anxiety) was the component most frequently used to estimate carers' well-being. However, it was somewhat surprising to find that some studies appeared to hypothesise that the absence of depression equals well-being. Several studies, besides focusing on carers' mental health did not include other measures reflecting concepts of hedonic and eudaimonic well-being. Other well-being studies focused on the physical and mental health of carers. Instead of measuring well-being, these studies appeared to be short versions of quality of life measures. Other studies, again, included items, such as anger, hostility and coping to measure well-being. While these measures are likely to influence carer well-being it is unclear how they reflect the concepts of hedonic and eudaimonic well-being.

These findings emphasise two important issues. First, there appears to be an absence of a clear distinction between the concepts of well-being and quality of life in the context of dementia care. As shown above, while many of the well-being studies do not specifically focus on measures reflecting hedonic and/or eudaimonic well-being, these concepts were picked up in WHO quality of life measure. This highlights the need for a discourse around the definition of the concepts well-being and quality of life in the context of dementia care as well as of their relationship to each other. Second, the diversity of approaches used to estimate well-being poses issues of interpretability. In the review, the Warwick-Edinburgh Mental Well-Being Scale was found to be the only well-being measure that had been tested for internal consistency and psychometric

properties (Orgeta & Lo Sterzo, 2013). In the literature on carer well-being, there needs to be greater consensus on how to measure well-being. The development of standardised measures with reliable psychometric properties could enhance the comparability of literature on carer well-being.

Finally, the comparison of qualitative studies focusing on carers' well-being and quality of life picked up on crucial aspects influencing a carer's ability to provide the care they would like to give and in order to live well. There were five common themes in both well-being and quality of life studies. First, carers experienced worries, stress, burden and grief. Second, carers expressed the need for and the ability to accept instrumental and emotional support from family members, friends and paid carers. Third, carers emphasised the importance and quality of the relationship between carer and care-recipient. Fourth, carers noted that concerns about the needs of the person with dementia takes over their own lives, and finally, carers recognised a need for personal space, social connections, belonging and recognition. No conceptual distinctions between studies focusing on carer well-being or quality of life could be made. In addition, these qualitative themes appeared to be largely absent from concepts explored in quantitative studies.

In sum it can be said that there is little and mostly inconsistent differentiation between concepts of quality of life and well-being of carers of people with dementia. Further theoretical discourse is needed to conceptualise well-being and quality of life in the context of dementia care to enhance consistency and comparability between studies focusing on the same concept, but also to distinguish between them.

2.5 Framework

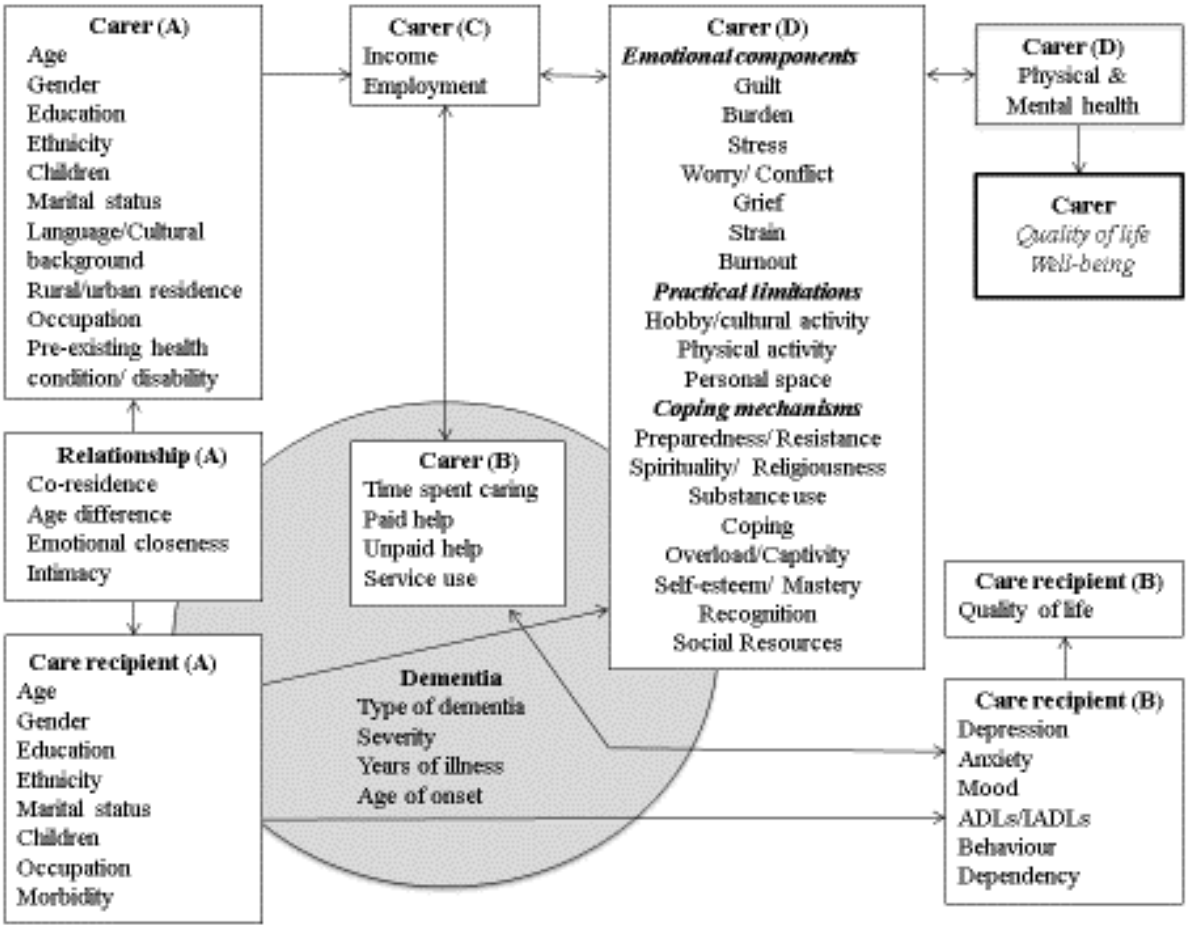
While the review presented above investigated outcome measures used to measure carer well-being and quality of life, this section focuses on the independent variables identified in the review. For this purpose, independent variables used in both quantitative and qualitative studies were listed and grouped into variables focusing on the carer and those reflecting the care-recipient. An overview of the tables can be found in Appendix 2 (Tables 2.3 – 2.6). A comparison of frequency of variable use gives an impression of aspects considered as relevant correlates of well-being and quality of life. There was substantial overlap in variables most commonly included in well-being and quality of life studies. The five most frequently used independent variables in both types of studies were carer gender, age, education, marital status and relationship to the care-recipient. Among variables focusing on the care-recipient, the five most frequently

collected variables were dementia severity, age and gender of the care-recipient, care needs (ADL/IADLs) and information on the presence and extent of challenging behaviour patterns. As observed with the outcome measures, a great variety of independent variables were explored in well-being studies. Examples include emotional closeness of the care dyad, carer sleep patterns or carer religiousness.

In order to better illustrate the variety of independent variables that have been considered to inform carer well-being and quality of life in the literature and to show how these variables might be associated with each other, I developed the framework illustrated in Figure 2.5.1. The two boxes labelled 'carer (A)' and 'care-recipient (A)' include characteristics of carer and care-recipient that existed prior to the care situation. These groups include variables such as age, gender, education and marital status. The box 'relationship (A)', sitting between the carer and care-recipient characteristics, illustrates variables indicating the relationship between carer and care-recipient. Next, the presence of dementia is illustrated as a circle to highlight the centrality of the illness and influence on people's lives. The presence and severity of dementia in the literature was measured through the variables such as type of dementia, severity, years of illness and age of onset. As dementia can directly influence people's care needs, their mental health and ultimately their quality of life, these aspects were illustrated in the boxes labelled 'care-recipient (B)'.

The presence of dementia, at least in part, determines people's care needs and therefore influences the degree of care that unpaid carers provide as well as the support they might seek. This is illustrated in the box labelled 'carer (B)'. The provision of care might also influence carer ability to pursue their employment and may affect household income (see Box 'carer (C)'). The different components outlined so far are likely to influence the way in which carers experience the provision of care (see boxes labelled 'carer (D)'). First, carers might experience emotional responses, such as feelings of guilt, burden or stress. Second, carers might experience practical implications to their lives, in that their relative's care needs might limit their own ability to pursue their hobbies or to engage in physical activity. The different aspects outlined previously might also influence how carers cope with the care situation. Jointly, these components might influence carers' physical and mental health and ultimately their well-being and quality of life.

Figure 2.5.1: Overview thesis framework



In the following each of the components considered in the framework will be explored in greater detail.

Carer characteristics

Key carer variables identified were carer age, gender, education, ethnicity and marital status. Together with the less frequently used variables, such as number of children, language and cultural background, residence in rural or urban areas and carer occupation, these variables were conceptualised as underlying factors of the care experience in both well-being and quality of life studies (see Appendix 2, Tables 2.3 and 2.4). They form a stock of characteristics carers bring into the caring situation.

In the literature, carer age was found to be negatively associated with both quality of life and well-being outcomes, meaning that older carers, often spouses, felt less burdened, experienced fewer worries, showed more family involvement and had to provide less support with ADLs than younger carers (Abdollahpour et al., 2015, p.53; Vickrey et al., 2009, pp.9-10; Holst & Edberg, 2011, p.553). Younger carers, frequently filial carers of people with dementia, experienced greater burden and pressure, but also were found to be more resourceful and expressed higher levels of spirituality and faith

compared to older carers (Holst & Edberg, 2011, pp.553-554; Rapp et al., 1998, p.43; Vickrey et al., 2009, pp.9-10).

Consistent findings between quality of life and well-being studies were also found when looking at carer gender. Female carers across studies experienced lower quality of life and well-being than their male counterparts. Women were found to experience depression and burnout, overload, captivity and depressive symptoms more frequently than men (Takai et al., 2011, p.101; Thomas et al., 2006, p.52; Fauth, Femia & Zarit, 2016, p.9; Orgeta & Lo Sterzo, 2013, p.5). However, the examination of carers' physical health by gender showed an interesting pattern. Before investigating differences in the gendered experience of care, it is important to point out that female carers often were younger than male carers (Thomas et al., 2006, p.52). Three studies found that physical health was better for females than males (Arango-Lasprilla et al., 2010, p.558; Fauth et al., 2012, p.705; Thomas et al., 2006, p.52). On the other hand, two studies reported that the health of female carers significantly depreciated over time. Those differences were not found to be significant among men (Holst & Edberg, 2011, p.554; Argimon et al., 2004, p.456). Instead, men were found to experience greater satisfaction with increasing length of caregiving (Holst & Edberg, 2011).

Carer education was only discussed in one study focusing on carer quality of life. Here it was found that carers had lower educational qualifications in comparison to non-caregiving controls (Arango-Lasprilla et al., 2010).

Differences in the experience of quality of life and well-being between ethnic groups were discussed in some studies. One study reported on ethnic differences between Caucasian and African-American carers. African-American carers were found to experience greater well-being. This difference appeared to be mostly influenced by greater levels of anxiety experienced among Caucasian carers (Haley et al., 2004). A similar comparison of levels of anxiety between Caucasian and Latina carers in another study did not show a statistically significant difference (Coon et al., 2004). Instead, Latina carers reported to experiencing challenging behaviour of the care-recipient as less stressful and evaluated their overall situation as more positively than Caucasian carers (Coon et al., 2004). Finally, non-white ethnicity of the carer was associated with greater spirituality and faith in two studies (Coon et al., 2004; Vickrey et al., 2009).

No evidence in relation to carer quality of life or well-being could be found for the variables marital status, the presence of children and carer occupation. Furthermore, no results for differences in carer language or cultural background could be found. A pan-European study by Bleijlevens and colleagues (2015), however, reported that

burden scores differ between countries. In this comparison, England scored second, with only carers in Estonia experiencing higher burden scores.

The final variable in this group considered influential on well-being is residence in rural or urban areas. The studies identified found that male carers in the UK had greater chances of receiving day care and sitting services than men providing care in rural areas. Similarly, female carers were found to receive fewer sitting services but more respite care in rural areas. The study also found that both men and women living in rural areas received greater support from family and friends than carers in urban areas (Tommis et al., 2007).

Care-recipient characteristics

The care-recipients' characteristics – such as age, gender, education, ethnicity, marital status, the presence of children, occupation and other morbidities - were conceptualised as factors existing independently of the dementia diagnosis. Even though the care-recipient's characteristics age and gender were included in around one-third of quality of life and well-being studies, none of these variables were discussed explicitly. Only Logiudice and colleagues (1999) reported a correlation between care-recipient age and the quality of life measure.

Relationship between carer and care-recipient

One important variable frequently collected is the relationship between carer and care-recipient. The two most common relationships between carer and the person with dementia are those between spouses or partners and between parents and adult children. However, even though more than half of well-being and quality of life studies described the relationship between carers and people with dementia included in their samples, only three quality of life studies and seven well-being studies reported on the relationship with carer well-being and quality of life. Well-being and quality of life outcomes did not differ significantly between spouses and filial carers in eight of the studies (Serrano-Aguilar, Lopez-Bastida, & Yanes-Lopez, 2006; Bell, Araki & Neumann, 2001; Gaugler et al., 2004; Rapp el al., 1998; Arango Lasprilla et al., 2009; Tommis et al., 2007; Gitlin et al., 2006). Fauth and colleagues (2012), however, found that daughters had better mental health scores than husbands, while Holst and Edberg (2011) showed that filial carers experienced greater burden. Only three well-being studies included further information on the relationship of the care dyad, such as the age difference between carer and care-recipient, their emotional closeness and/or intimacy

as factors shaping the relationship (Ask et al., 2014; Fauth et al., 2012; Gaugler et al., 2004).

It is hypothesised that the quality of the relationship affects the level and quality of care provided but also influences carer well-being. Particularly the quality of relationship, emotional closeness and intimacy may be affected by the illness. Fauth and colleagues (2012) investigated the effect of relationship closeness on carer affect. The study found that care dyads who reported greater closeness at baseline were more likely to experience an increase of carer affect over time. Furthermore, carers reporting closeness at baseline were found to experience significantly fewer depressive symptoms at baseline, but this protective effect did not last over time. Instead it led to 'significant decreases in mental health scores over time' (Fauth et al., 2012, p.705). Additionally, the experience of a loss in relationship closeness predicted a reduction in physical health scores over time. Carers in qualitative studies reported moments of encouragement as times when the care-recipient 'woke up' from the dementia and engaged in interaction or expressed his or her appreciation for the support received. Carers described such moments as 'a sense of reciprocity' (Hasselkus & Murray, 2007, p.14; Jones, Tudor Edwards & Hounesome, 2014; Vellone et al., 2008).

Co-residence is another important variable that may alter carer well-being and quality of life and was closely linked to the carer care-recipient relationship. Both quality of life and well-being outcomes were found to be lower for co-resident carers (Bruvik et al., 2012; Ask et al., 2014). Furthermore, filial carers co-residing with a parent with dementia in rural areas exhibited lower Mental Component Summary Scores than their counterparts living in urban areas (Tommis et al., 2007). Carers' whose care-recipient had moved into institutional care settings were found to experience greater life satisfaction (Ask et al., 2014).

The presence of dementia, type and severity

The presence of dementia, its type, severity, time since onset and the age at which dementia became apparent were found to influence a number of care-recipient and carer variables. Most studies estimating carer well-being or quality of life included a measure of severity (e.g. Orgeta et al., 2015; Gaugler et al., 2015; Santos et al., 2014). Mixed evidence was found for the impact of dementia severity on the well-being or quality of life of carers. Among the studies investigating carer quality of life, three studies indicated that caring for people with advanced dementia negatively affected carer quality of life (Abdollahpour et al., 2015; Andrieu et al., 2007). The study by Bell, Araki and Neumann (2001), however, could not observe a statistically significant

difference in the quality of life of carers looking after people at different stages of dementia. When looking at research focusing on carer well-being a similar picture occurred. The review by Pinquart and Sörensen (2004) as well as the study by Chappell and Reid (2002) did not detect severity of dementia to significantly influence carer well-being. They did, however, find that cognitive impairment and increased functional impairment led to the reporting of greater problems with care-recipient behaviour. Only Tommis and colleagues (2007) presented evidence that carers' mental and emotional health worsened with increasing dementia severity.

Indicators of the type of dementia, years of illness and age of onset are found less frequently in both types of studies (Santos et al., 2014; Takai et al., 2011; Duggleby et al., 2011; Argimon et al., 2004; Fauth, Femia & Zarit, 2016; Fauth et al., 2012). Thomas and colleagues (2006) reported that carers who looked after people with dementia with Lewy body experienced lower levels of quality of life than those caring for someone with Alzheimer's disease.

Qualitative research touched on a number of aspects directly linked to the diagnosis of dementia as influential on carers' well-being and quality of life. Difficulties in obtaining a diagnosis, scattered information about the illness as well as the level of attention received post-diagnosis were points that carers mentioned in relation to their quality of life (Jones, Tudor Edwards & Hounesome, 2014).

Care-recipient mental and physical health, dependency and behaviours

The dementia-related variables discussed above were also understood to influence care-recipients' mental health, the development of challenging behaviour, and people's degree of dependency indicated through ADLs and IADL needs. Dementia may also affect care-recipients' overall health status and mood.

Most frequently used in both carer well-being and quality of life studies were care-recipients' ADL and IADL limitations to indicate care needs. The second most commonly examined domain was challenging behaviour. While Papastavrou and colleagues (2014) could not establish a direct association between the need for ADL support and carers' quality of life, other studies found associations between ADL and IADL dependency and carer overload, captivity and depressive symptoms as well as between perceived social support and formal service use (Fauth, Femia & Zarit, 2016; Chappell & Reid, 2002). Similarly, while one study found that challenging behaviour of the care-recipient impacted on carers' well-being and quality of life (Coen et al., 1999), two other studies identified a direct association to carer burden, but not to carer well-being (Holst & Edberg, 2011; Chappell & Reid, 2002).

A number of quality of life studies and one study on carer well-being also included the presence and degree of care-recipient depression. Care-recipients' anxiety, mood, health status or the presence of co-morbidity in both types of studies were only measured sporadically (Orgeta et al., 2015; Gaugler et al., 2015; Graff et al., 2007; Logiudice et al., 1999; Raina et al., 2004; Arango Lasprilla et al., 2009; Holst & Edberg, 2011). Limited evidence was identified regarding the influence of the care-recipient's health status and anxiety on the family carer and no evidence was found for the relationship between carer well-being or quality of life and care-recipient's depression. However, both care-recipient's anxiety symptoms and physical impairments were negatively related to carer quality of life (Santos et al., 2014; Pinquart & Sörensen, 2004). Pinquart and Sörensen (2004, p.439) further found that in studies with different well-being outcome measures, such as 'perceived quality of life, combinations of life satisfaction and positive affect', the association between well-being and physical health was stronger than when carers were only assessed on life satisfaction and positive affect.

As Figure 2.5.1 illustrates, it was understood that these variables further influence care-recipients' quality of life. Care-recipient quality of life, using the QoL-AD measure outlined earlier in this chapter, was used as an independent variable informing carer quality of life in seven out of 20 quality of life studies (Orgeta et al., 2015; Santos et al., 2014; Camic, Williams & Meeten, 2011; Bruvik et al., 2012; Inouye et al., 2009; Graff et al., 2007; Thomas et al., 2006). However, no direct relationship between care-recipient quality of life and the quality of life or well-being of the carer was reported in the studies reviewed.

The care experience

The care experience in the quantitative literature most frequently is measured using indicators of the time spent caring, referring to either hours per week or months or years of providing care to a relative with dementia (Bleijlevens et al., 2015; Papastavrou et al., 2014; Kuo et al., 2014; Bartfay and Bartfay, 2013; Bruvik et al., 2012; Kolykhalov et al., 2011; Duggleby et al., 2011; Arango-Lasprilla et al., 2010; Vickrey et al., 2009). Among quality of life studies, an increase in time spent caring was associated with challenging behaviour and psychotic symptomatology (Kolykhalov et al., 2011). Another study found time spent caring to be associated with the level of dependency (ADL and IADL impairment) and degree of cognitive impairment. Only one study found a negative association between time spent caring and carer quality of life (Vickrey et al., 2009). Chappell and Reid (2002) investigated the impact of time spent

caring on carer burden and found a positive association. They also found that high carer self-esteem and the reporting of getting breaks reduced the probability of an increased burden score.

Less frequently measured were the presence of paid and unpaid help as well as the use of other dementia care-related services, such as respite. Studies considering these aspects can be found more frequently in well-being studies, but have also been identified in some quality of life studies (Gaugler et al., 2015; Thomas et al., 2006; Logiudice et al., 1999; Chenoweth et al., 2016; Ask et al., 2014; Chappell & Reid, 2002; Holst & Edberg, 2011; Roscoe et al., 2009; Au et al., 2009; Charlesworth et al., 2008; Pot et al., 2005; McConaghy & Caltabiano, 2005; Raina et al., 2004). No quantitative evidence was found to investigate the impact of paid help on carer well-being and quality of life; however qualitative studies could offer some insights. The relation of paid care staff with the carer appeared crucial when carers spoke about perceived benefits. Where paid carers met family carers' needs and set the right tone and when carers felt that the care-recipient liked the paid carer, the rapport was full of praise. If, however, there was a problem in one or more of these interactions carers appeared to be negatively affected by the situation, expressing feelings of guilt at not being able to look after their relative by themselves (Hasselkus & Murray, 2007; Jones, Tudor Edwards & Hounesome, 2014; Duggleby et al., 2011; Shuter, Beattie & Edwards, 2014).

The beneficial effect of additional unpaid care support to carer quality of life became evident in both quantitative and qualitative studies (Abdollahpour et al., 2015; Duggleby et al., 2011; Wexler Sherman, 2012). A study focusing on carer well-being found that unpaid support in the care situation was positively associated with carers' ability of getting a break (Chappell & Reid, 2002). Some evidence in both quality of life and well-being studies pointed towards the positive effect of carers' use of services. Bartfay and Bartfay (2013, p.109) found that carers who attended support groups had better ratings in the categories 'memory' and 'ability to have fun'. Another study found that attending adult day services reduced carers' worry and feelings of role overload (Gaugler et al., 2003). In contrast, Chappell and Reid (2002) argued that the use of service was not associated with self-esteem, burden or well-being, but instead pointed out that the usefulness and willingness to engage with services may depend on the level of cognitive impairment. Carers of people with advanced memory problems might choose fewer services than carers of people living with less severe dementia (Chappell & Reid, 2002). However, even though carers recognised the benefits of existing unpaid

instrumental and emotional support available to them, the majority of carers in qualitative studies expressed the wish for more support of this kind (Wexler Sherman, 2012).

Carer income and employment

The degree to which carers were able to provide dementia care may in part also be determined by carers' income and employment. It was found that family members were more likely to become carers if they were not in formal employment or had a lower income than other family members (ONS, 2013a). Therefore, these variables were illustrated separately from carer characteristics as the presence of dementia might influence carers' income and employment status. Both variables were frequently measured in well-being and quality of life studies. However, carer income was discussed with respect to quality of life. While one study found that quality of life increased with income, another study found that quality of life scores were highest for carers with lower income (Duggleby et al., 2011; Papastavrou et al., 2014). Carers in a qualitative study expressed wishes for material help as well as the desire to buy things they liked or to be able to afford a holiday (Vellone et al., 2008).

Carers emotional responses, practical implications on their everyday lives and coping mechanisms

The group of variables in the illustrated framework labelled as 'Carer (C)' listed three types of intermediate care outcomes that in the literature were understood to influence carer well-being and quality of life. These are carers' emotional responses to their experience, practical implications on carers' everyday lives and carers' coping mechanisms.

Carers' emotional responses to their personal care experience were measured through variables such as guilt, burden, stress, worry, conflict, grief, strain and burnout. No evidence of the impact of carer guilt on quality of life or well-being could be found in quantitative studies, but qualitative research showed that carers frequently experienced feelings of guilt when they had to prioritise their own needs over those of the care-recipient, when they could not foresee events that would cause problems, when they left their relatives with a paid carer or when the care-recipient was moved into institutional care (Hasselkus & Murray, 2007; Jones, Tudor Edwards & Hounesome, 2014; Vellone et al., 2008).

Carer burden was uniformly found to be negatively associated with quality of life measures but also other variables, such as depression (Moreno et al., 2015; Bleijlevens

et al., 2015; Abdollahpour et al., 2015; Santos et al., 2014; Papastavrou et al., 2014; Schölzel-Dorenbos et al., 2009; Bell, Araki & Neumann, 2001). Findings in carer well-being studies showed a negative relation between burden and carer well-being (Chappell & Reid, 2002; Coen et al., 1999; Arango Lasprilla et al., 2009). Carers in qualitative research expressed the experience of burden, particularly in relation to family conflicts over the person with dementia's care, but also through the feeling of 'being consumed by responsibility' (Wexler Sherman, 2012; Duggleby et al., 2011, p.93). Jones, Tudor Edwards and Hounsome (2014) found that burden increased with the degree of kinship.

Linked to the concept of burden, but discussed separately was the experience of stress, worry, strain and grief among carers of people with dementia. The experience of carer stress was discussed in well-being studies, which found a negative association (Orgeta & Lo Sterzo, 2013). Pinquart and Sörensen (2004) found that in particular the experience of depression was associated with carer stressors. Carers of people with dementia who exhibited inappropriate sexual behaviours but also other behavioural problems, such as hallucinations, experienced very high levels of stress (Arango Lasprilla et al., 2009). Carer stress and worry was also expressed in qualitative work. Management of changing needs and safeguarding the care-recipient during day and night time were examples of worries carers experienced (Spring, Rowe, & Kelly, 2009). Furthermore, carers expressed the lack of predictability of the progression of the illness as well as concerns of being a burden to others as worries (Jones, Tudor Edwards & Hounesome, 2014; Vellone et al., 2008).

Carer gain and strain were only discussed in relation to carer well-being studies. Stressful and burdening factors of dementia care such as cognitive loss and behavioural problems played an important role in determining carers' experience of strain and gain (Rapp & Chao, 2000). While the majority of carers reported experiencing strain, this did not mean that carers would stop reporting the meaning and positive affect they drew from looking after their relative with dementia (Rapp & Chao, 2000; Roscoe et al., 2009; Gitlin et al., 2006). Finally, carers reported experiencing an ongoing grief process due to the nature of dementia leading to a gradual loss of the care-recipient's cognitive abilities. After the care-recipient had passed away, some carers reported the feeling of having lost their relative twice (Shuter, Beattie & Edwards, 2014).

The practical implications of dementia care on carers' lives considered in this framework are based on the evidence from the literature, where limited abilities to pursue hobbies, cultural or physical activities and a loss of personal space were

discussed. Bleijlevens and colleagues (2015) discussed carers' ability to pursue leisure activities and engagement with cultural aspects. The study found that carers' activities were more negatively affected where carers provided dementia care at home in the community compared to those looking after a relative in an institution. In other studies, the ability to pursue leisure activities or even the participation in group activities with the care-recipient, such as singing in a choir, were viewed positively and could also enhance feelings of belonging (Chenoweth et al., 2016; Camic, Williams & Meeten, 2011; Vellone et al., 2008).

In the qualitative literature the concept of personal space, social connections and the ability to maintain some leisure activities received some attention. Carers expressed their need for personal space as time that was reserved for the carer away from the care-recipient. Carers who were unable to maintain a degree of personal space expressed frustration about their loss of independency and some felt they experienced an occupational and/or biographical disruption. This meant that carers felt they lost a large degree of autonomy in decision making (Jones, Tudor Edwards & Hounesome, 2014; Vellone et al., 2008; Wexler Sherman, 2012; Spring, Rowe, & Kelly, 2009; Hasselkus & Murray, 2007).

The way in which carers deal with their care responsibility and the potential resulting practical and emotional experiences discussed are understood to further influence carer well-being and quality of life. Some studies directly looked into the concept of coping to better understand carer well-being. For instance, the coping mechanisms 'wishful thinking' and 'blame' were discussed in the literature. Both coping mechanisms were associated with greater anxiety, depression and the number of reported medical conditions (Snyder et al., 2015; Orgeta & Lo Sterzo, 2013). 'Carer religion' and 'spiritual involvement' were other coping mechanisms explored in the literature. Roscoe and colleagues (2009) found high positive correlations between spirituality, life satisfaction and self-rated health as well as a negative relation with depressive symptoms. As discussed above, it appears that religion plays a greater role among some ethnic groups (Haley et al., 2004).

Similarly, the concepts carer overload, captivity, self-esteem and mastery were understood to influence the way in which carers handle their situation and to influence carers' quality of life and well-being. Carer overload appeared to be associated with resistance to care as well as with resistance to care appraisal. Captivity was also found to be linked with resistance to care appraisal (Fauth, Femia & Zarit, 2016). Mastery, meaning the feeling that carers were in control of life's problems, was positively

associated with well-being and negatively with depression and burden (Pinquart & Sörensen, 2004; Chappell & Reid, 2002; Roscoe et al., 2009). Bleijlevens and colleagues (2015), in their comparison of unpaid carers in community and institutional care settings, found that carers in the community showed lower carer self-esteem.

Another concept associated with carers' ability to be in charge of the caring situation was the notion of carer preparedness and resilience. One study found that those who showed 'the highest scores of positive readiness' also had the highest quality of life scores (Duggleby et al., 2011, p.4). Social resources and recognition were related concepts considered in the literature. The term 'social resources' includes the ability to reach out for help and support as well as the presence of a support social circle, including family and friends. Evidence uniformly showed that carers who are able to seek out support, who had good relationships with their family and reported close friends experienced greater quality of life and well-being (Duggleby et al., 2011; Inouye et al., 2009; Orgeta et al., 2013; Chappell & Reid, 2002; Rapp et al., 1998). Carers whose care-recipient exhibited greater physical dependency 'tended to receiver greater levels of social support' (Chappell & Reid, 2002). Where, however, carers felt abandoned and lonely due to the lack of interest by family members or limited resources, carers reported feelings of isolation (Wexler Sherman, 2012; Duggleby et al., 2011). On the other hand, carers highly rated community-based support, such as help from the police, neighbours, charities, the mail lady, the barber, the veterinarian, the pastor and others (Hasselkus & Murray, 2007).

Furthermore, as the dementia progresses, carers spend increasing amount of time and effort looking after their relative with dementia. Due to the nature of the illness social interaction and the care-recipients' ability to express their love and gratitude gets lost over time. Many carers expressed a need for recognition of the support they provide for their relative as a form of judgement of their own performance (Hasselkus & Murray, 2007; Jones, Tudor Edwards & Hounesome, 2014).

Physical and mental health

The final and most frequently measured components of the framework identified to inform carer well-being and quality of life were carers' physical and mental health. Both quality of life and well-being studies show that dementia care can have negative impacts on carers' physical health. Comparisons between home carers and carers supporting their relative with dementia in institutional settings as well as comparison between carers and non-carers showed that carers of people with dementia, and especially those in a home care environment, experienced worse physical health

(Bleijlevens et al., 2015; Arango-Lasprilla et al., 2010). Similarly, a study focusing on carer well-being found that people looking after a relative with dementia reported worse health than carers looking after 'children with physical and/or intellectual disabilities and carers of adults with physical disabilities' (Chenoweth et al., 2016, p.8). Other work showed that good physical health is related to greater well-being and life satisfaction (Orgeta & Lo Sterzo, 2013; Roscoe et al., 2009). This evidence is supported by qualitative findings, with carers reporting sleep and energy loss as well as indicators of depression, such as reduced motivation to 'carry out routine tasks of life or engage in self-care' (Duggleby et al., 2011; Spring, Rowe, & Kelly, 2009, p.42).

As discussed in the literature review, carers' physical and mental health were components included in most outcome measures. Some studies even appeared to equate well-being with the absence of depression. In the literature, mental health components were therefore more frequently used in quality of life studies (n=15) than in studies focused on well-being (n=6). Studies consistently report that carers suffering from anxiety and depression also experienced lower physical health as well as reduced overall quality of life and well-being (Roscoe et al., 2009; Moreno et al., 2015; Santos et al., 2014; Papastavrou et al., 2014; Takai et al., 2011; Belle et al., 2006; Orgeta & Lo Sterzo, 2013; Pinquart & Sörensen, 2004; Arango Lasprilla et al., 2009).

Some studies further investigated the role and interaction of mental health aspects. Santos and colleagues (2014) found that among carers of people with mild cognitive impairment, carer scores of depression were associated with challenging behaviour by the care-recipient. In addition, carer depressive symptoms were found to be associated with the quality of relationships to friends and carer mood. Among carers of people with moderate dementia, depression was associated with carer anxiety and overall quality of life. These findings were in line with two studies focusing on carer well-being, reporting an association between challenging behaviour in the care-recipient and carer mental health scores (Fauth et al., 2012; Arango Lasprilla et al., 2009). In addition, Fauth and colleagues (2012) found that where carers experienced more health conditions at baseline, this predicted an increase in their mental health scores over time. This is consistent with findings from another study that reported a positive correlation between the experiences of care related stress and increased levels of depression (Roscoe et al., 2009). Similarly, Andrieu and colleagues (2007), reported that carer depression was associated with the level of disability of the care-recipient.

2.6 Summary and conclusion

This chapter pursued three aims. First, it aimed to clarify the understanding of how well-being and quality of life of family carers of people with dementia were conceptualised. Second, it provided an overview of how well-being and quality of life were measured in the literature and discussed how the measures identified sat with the theoretical concepts. Third, it provided a framework of variables that influence carer well-being and quality of life based on the results from the literature review.

The comparison of well-being definitions highlighted the two distinct but related theoretical approaches eudaimonia and hedonism. However, further distinctions between personal, psychological, subjective and objective well-being exist. A comparison of measures used to estimate these approaches showed that personal and psychological well-being sits well with the concept of subjective well-being. In the context of this thesis, a focus on subjective well-being, which includes people's physical and mental health, their emotional well-being and their ability to pursue a life that enables room for happiness and personal growth in line with the well-being definition in the Care Act (2014) appears most appropriate. A comparison between the concepts of well-being, quality of life and health-related quality of life showed that differences were small, as all definitions emphasised the importance of physical and mental health as well as social components.

The conceptual difficulty of distinguishing between well-being and quality of life of carers of people with dementia became even more apparent when investigating how these concepts were measured in the literature. While some homogeneity due to the availability of standardised measures was found among quality of life measures, carer well-being was frequently measured through scales investigating carers' mental health. Some studies, additionally explored carers' life satisfaction or happiness. This showed that the only consensus in measuring carer well-being appears to be the emphasis on depression and anxiety or the absence thereof.

Finally, an overview of variables used in the literature to inform carer well-being and quality of life was provided and presented as a framework. This framework differentiated between carer and care-recipient variables. It also aimed to provide an overview of how the different variables are related to each other and how they inform well-being. A summary of evidence from the literature was provided for each of the variable groups.

Chapter 3

Methods

This chapter provides an overview of the methods used to address the research questions outlined in Chapter 1. First, it offers a rationale for the use of mixed methods research design and outlines the theoretical framework from which this thesis has been approached. Second, it explains how this thesis sits within the MODEM project and provides information on other data sources used. Finally, this chapter describes the methodological steps taken for the results of the analysis presented in Chapters 5, 6 and 7.

3.1 Mixed methods research design

This research aims to understand if and how the well-being and quality of life of carers of people with dementia in the community varies by gender and age. As outlined in Chapter 1, this question will be responded to with the help of five subsidiary research questions. Three of these questions (research questions 2, 4 and 5) are explanatory in nature, requiring a deductive, quantitative approach. Research question 3, on the other hand, has a contextual function benefiting from inductive, qualitative research.

Mixed methods research, in social science, has increasingly been recognised as an approach that allows researchers to 'integrate quantitative and qualitative research approaches to best understand a research problem by capitalizing on their complementary strengths and differences' (Plano Clark, 2017, p.305). The approach to this research, as outlined in Figure 3.1, in part was driven by the goal to pursue a sequential approach where qualitative evidence helps to inform quantitative analysis and in part by the timeline of the Modelling Outcome and Cost Impact of Interventions for Dementia (MODEM) project.

In 2014 I was awarded an ESRC scholarship to pursue my PhD studies as part of the MODEM project. Between the start of my PhD journey in October 2014 and the beginning of the data collection in September 2015 I was given the great opportunity to contribute to the discussion around which questionnaire items to include and to participate in the development and amendment of questions included in the cohort survey. This meant that variables included in the quantitative analysis had to be determined prior to the qualitative interviews aiming to explore aspects influencing carer quality of life and were therefore primarily based on the literature review (see Chapter 2). The design of the qualitative study was then informed by the discourse

around designing the MODEM questionnaire, but I was also able to benefit from advice from experts by experience. The MODEM reference group provided important insights and feedback during the planning of the qualitative study. While the consecutive two waves of survey data collection for the cohort MODEM study were under way, I was able to conduct qualitative interviews with 25 carers who also participated in the MODEM cohort study. This led to quantitative and qualitative MODEM data being collected concurrently.

Even though data collected as part of the MODEM cohort study contains detailed information on carers, the data may not be representative of family carers of people with dementia in England (see Section 3.2.1). In order to understand whether findings based on the analysis of the MODEM cohort also are likely to reflect other carers in England, I explored whether population-representative data of carers of people with dementia in England was available for comparison. However, no dataset could be identified. I then explored other data sources on carers of people with dementia in England that would allow for a comparison with MODEM data.

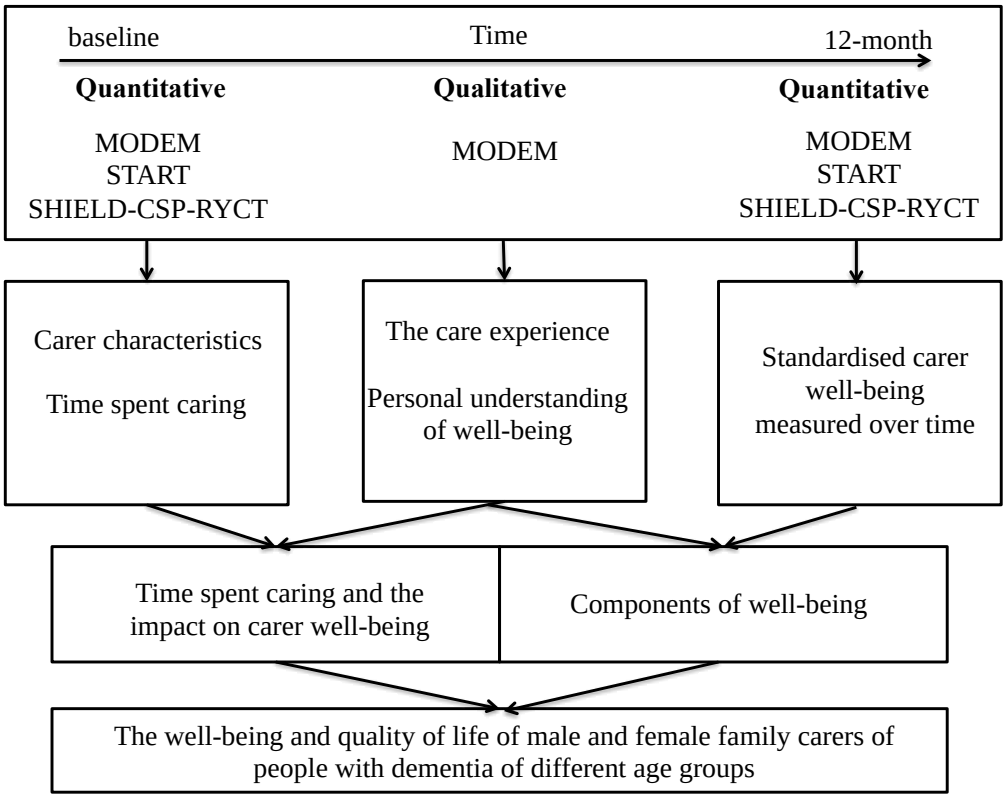
I identified the two trial datasets START and SHIELD-CSP-RYCT as studies that had been collected in recent years and contained comparable information on carers. The databases were kindly made available to me by the lead investigators Professor Gill Livingston and Dr Georgina Charlesworth. Together with MODEM, START and SHIELD-CSP-RYCT data were used to respond to research questions 2, 4 and 5

Data analysis was then conducted in an intentionally sequenced fashion (Plano Clark, 2017; Ritchie & Ormston, 2014). First, simple quantitative analysis was conducted comparing carer and care-recipient characteristics in MODEM, SHIELD-CSP-RYCT and START to those in population-representative datasets. Next, qualitative interview data was analysed. Following the data analysis, I was able to benefit from the MODEM reference group who provided me with comments and feedback on my findings.

Finally, the two quantitative research questions were responded to. Findings from the qualitative study presented in Chapter 5 as well as the framework presented in Chapter 2 informed the selection and interpretation of variables explored in the quantitative analysis presented in Chapters 6 and 7. Research question 4 focused on carer well-being over time and used baseline and 12-month follow-up data, while research question 5 investigated factors influencing time spent caring. The findings from the literature review and the resulting framework, as well as findings from the qualitative interviews, helped me to reflect on the results of the analysis presented in

Chapters 5 and 6. While results from each of the research questions stand on their own, they have also helped to inform the interpretation of the others.

Figure 3.1 The mixed methods approach applied in this thesis



3.2 Theoretical Framework

This thesis is argued from a critical realist perspective. 'Critical realism' or 'subtle realism' makes an important distinction between ontology and epistemology. Its ontological perspective maintains that reality exists 'independently of those who observe it' (Ormston et al., 2014, p.21; Archer, 1998). Whiltshire (2018, p.532) describes this with the image of a falling tree in the woods. Even in the absence of anyone hearing the tree falling, it would have still made a noise.

Epistemologically, however, in contrast to positivist approaches, critical realism emphasises the social production of knowledge. Bashkar (1975, p.16) describes 'knowledge […][as] a social product, produced by means of antecedent social products'. Maxwell (2012, p.9) emphasised that critical realism 'reject[s] the idea of 'multiple realities', however, it does recognise the existence of different 'valid perspectives of reality' (see also Wiltshire, 2018, p.532). This means that the interpretation of reality is based on social norms. These in turn are understood to have been socially constructed. Therefore, the interpretation of events may depend on

people's underlying social concepts, implying the validity of different perspectives of reality.

As a consequence, critical realists are not just interested in understanding the underlying reality, but also to explore people's perceptions and how these perceptions (social norms) were shaped. This approach enables a philosophical compatibility of mixed methods research, where qualitative and quantitative methods can contribute to answer different but related research questions (Bryman & Becker, 2012, p.334).

3.3 Introducing the data

3.3.1 The Modelling Outcome and Cost Impact of Interventions for Dementia (MODEM) project

The MODEM project aims to explore 'how changes in arrangements for the future treatment and care of people living with dementia, and support for family and other unpaid carers, could result in better outcomes and more efficient use of resources' (Comas-Herrera et al., 2017, p.25). Ethical approval (15/IEC08/0005) was obtained in February 2015.

In order to collect some of the information needed for the models, we followed 300 people with dementia and their carers for 12 months. Participants were interviewed at baseline and 12-month follow-up (see Appendix 3.1). Information was collected through a number of standardised questionnaires, such as the EQ-5D or the Mini-Mental State Examination (MMSE) to assess presence and severity of dementia.

Furthermore, we collected information on service use with the help of a study-specific version of the Client Service Receipt Inventory (CSRI). The adaptable research instrument initially developed by Beecham and Knapp (1999) helps to gather data on demographic and socio-demographic information, accommodation and living situation, employment history, earnings and benefits, service use and information on support provided by unpaid carers. Through my involvement in the development of a version of the CSRI appropriate for the purpose of the MODEM cohort study it was possible to include a number of questions for unpaid carers relevant to my PhD. Examples of questions we specifically developed for MODEM are proximity between carer and the person with dementia, several questions investigating sleep patterns of carers (some of which have been taken from the English Longitudinal Study of Ageing (ELSA)) and detailed information on health and social care service use by carers. Furthermore, my involvement in the project allowed me to include an amended version of the Resources Utilization in Dementia questionnaire; a measure that helps to collect information on

time carers spent on different care tasks. The measure and its use will be discussed in detail in Section 3.5.

At baseline the cohort consisted of 318 people with dementia and their 318 carers. (The aim was to recruit 100 people with mild dementia, 100 moderate and 100 severe.) A clinical diagnosis of dementia (ICD-10 criteria) and the presence of an unpaid or formal carer were inclusion criteria. The emphasis on equal numbers of people with dementia, the limited sample size and the limited regional diversity means that data may not be representative of carers of people with dementia in England. For this research only unpaid carers providing care for a person with dementia in the community will be considered.

In addition, my involvement in the project enabled me to plan and conduct qualitative interviews with 25 unpaid carers who also participated in the cohort study. Detailed information on the qualitative component of this study can be found in Section 3.4.

3.3.2 SHIELD-CSP-RYT and START: two trials focusing on carers

The Support at Home: Interventions to Enhance Life in Dementia: Carer Supporter Programme – "Remembering Yesterday Caring Today" (SHIELD-CSP-RYCT) is a 2×2 factorial single-blinded randomised controlled trial. Randomised data collection was conducted between January 2009 and March 2012. People with dementia and their unpaid carers were recruited from community settings in North East London, Norfolk, Northamptonshire, and Berkshire through 'leaflets, flyers and posters' and invitations in local papers and newsletters. Participants were also recruited via gatekeepers such as the Alzheimer´s Society and Admiral Nurses. CSP-SHIELD-RYCT excluded people without the ability to speak English. Participation in other studies as well as the presence of terminal illness, the experience of congenital learning disability or non-progressive brain injury in carer or patient were further reasons for exclusion.

Following baseline assessment, participants were randomised into the 'Carer Supporter Programme' (CSP) and treatment as usual (TAU) groups. Participants in the CSP group had access to a Carer Supporter over 10 months. Carer Supporters are people who have experience in providing unpaid dementia care and have received training on providing emotional and informational support to newer carers. Participants in the TAU group did not receive any study-specific interventions but could continue to access services available for carers of people with dementia. Following this first randomisation, each group was further randomised into two categories.

Participants of the initial CSP group either remained in the CSP group or were

allocated into a CSP/RYCT (Remembering yesterday, caring today) group. Similarly, participants of the initial TAU group either remained in the TAU group or were allocated into a TAU/RYCT group. The 'Remembering Yesterday, Caring Today' (RYCT) reminiscence group therapy is a twelve-week intervention for people with dementia and their carers, offering additional training for unpaid carers on listening and communication skills. Following the initial sessions, monthly reunions were offered for seven months. Participants of the TAU/RYCT intervention also had access to the RYCT intervention but received no other intervention. All participants of the study were provided with information on resources in their area (Charlesworth et al., 2011). More detailed information on SHIELD-CSP-RYCT study can be found in Appendix 3.2.

The StrAtegies for RelaTives study (START) is a randomised-controlled trial. The data was collected from November 2009 to February 2012. Participants were drawn from mental health and memory services in London and Essex and were interviewed at baseline and up to two years after randomisation. Participants were grouped into intervention and treatment as usual arms (TAU) with an allocation of 2:1. Participants enrolled in the intervention arm received eight therapy sessions of the 'Coping with Caregiving programme' developed in the United States but adapted for the UK context. Participants of the TAU group received no specific intervention but had access to care in line with the clinical guidelines for good dementia care by NICE (Livingston et al., 2014a, 2014b). For the purpose of this study, baseline and 12-month follow-up data will be used. A more detailed description of the START study can be found in Appendix 3.3.

3.3.3 Other datasets used in this thesis

The Population Census (2011) contains data from all people residing in the country on a given day. It collected data on socio-demographic as well as policy relevant information, such as information on health and use of transportation. Aggregate Census 2011 data was obtained from the INFUSE service provided by the University of Manchester (InFuse, 2017; ONS, 2015).

The English Longitudinal Study of Ageing (ELSA) comprises a representative sample of the English population aged 50 and above. Data has been collected in seven waves since 1998. Data collected is related to 'health and disability, biological markers of disease, economic circumstance, social participation, networks [and] wellbeing' (The Institute for Fiscal Studies, 2011). Data from the most recent wave available at the time of analysis (Wave 6) was collected in 2012 and includes a refreshment sample of people

aged 50-55. ELSA Wave 6 includes 10,601 participants (The Institute for Fiscal Studies, 2011). Data was obtained from the UK Data Service.

3.3.4 What the quantitative datasets offer and what they cannot do

This research primarily was built on and around the MODEM cohort study. The two trials SHIELD-CSP-RYCT and START, which contained similar variables as collected in MODEM, were kindly made available to me. The availability of the three datasets allowed me to pursue similar analysis using the three datasets. As each of the datasets had been collected for different purposes, each dataset contained information that was not available in the other two. Furthermore, the collection of different standardised measures in each of the datasets enabled the exploration of different well-being proxy-measures in line with findings from the literature review in Chapter 2. On the other hand, different foci in the three datasets limited the availability of comparable variables, which meant that it was impossible to pursue pooled analysis of the three datasets.

Another limitation in the analysis of the datasets is common to dementia research in general. Identifying and recruiting people with dementia and their carers into studies can be difficult from a practical as well as an ethical perspective. In order to overcome these barriers participants in dementia research tend to be recruited through medical or care-related contacts such as General Practitioners, memory clinics, self-help groups or social services to name just a few examples. It can be assumed that people with dementia and carers accessing these services also have knowledge and agency of accessing other support available. This may differentiate people in touch with services from people unable to identify need of and access to support and therefore may affect the results of the study.

3.4 MODEM: qualitative study

The qualitative research presented in Chapter 5 is based on interviews I conducted with 25 carers of people with dementia who also participated in the MODEM cohort study. Ethical approval for the study was obtained from the Social Care Research Ethics Committee (16/IEC08/0012) and a researcher passport was issued by the Sussex Partnership NHS Foundation Trust. The study protocol and the ethics approval letter can be found in Appendices 7 and 8. The study responds to the research question: ‘Are there differences in how husbands, wives, daughters and sons of people with dementia experience the provision of care and how they construct well-being?’ In the following I outline different methodological aspects of the study.

3.4.1 Sampling and recruitment

Approximately half-way through the first wave of MODEM cohort data collection (see Section 3.2.1) we obtained ethical approval to change the consent form so that carers could opt in to be re-contacted for further research. This strategy enabled me to contact 146 carers who participated in the cohort study about this qualitative research. Carers were informed in writing that the qualitative study aimed to learn about aspects that influence the well-being of people who provide care to a person with dementia. In order to be included in this study, participants had to provide unpaid care to a person with dementia and be able to communicate in English.

The study used an opt-out approach, which meant that carers who received the invitation letter could contact me to declare their wish not to participate in this research. Carers who did not opt-out could be re-contacted by phone with a request for participation in the study. This approach was used to 'produce a more comprehensive and representative sample frame' and to avoid self-selection (Ritchie et al., 2014, p.123). Six carers used the opportunity to opt-out. Two re-occurring reasons for the decline were that the person with dementia had passed away in the meantime or that they did not have the time and capacity to further engage with research. In addition, eight carers contacted me to express their interest in the study. These self-identifiers were thanked for their interest in the study and informed that in order to enable everyone to take part potential participants would be selected at random.

I aimed to interview roughly equal numbers of husbands, wives, daughters and sons. In the literature, sample sizes between 12 and 50 are suggested to provide a good insight (Ritchie et al., 2014, p.117). In order to reflect diversity within the subgroups, but also for reasons of feasibility I decided to aim to interview around 30 carers, roughly evenly split into the four carer groups. A total of 42 wives, 36 husbands, 29 daughters and 11 sons were considered for the follow-up phone call. As outlined in Chapter 1, this research focuses on carers supporting people with dementia in the community. Before re-contacting sons for this study I learnt that all of them either supported a parent living in institutional care settings or that their parent had recently passed away. In order not to lose sons from the analysis I decided to include the adult sons willing to participate, irrespective of the care setting. For comparability, the sample of daughters was extended to also include those caring for a parent in institutional settings (n=29). Potential participants were re-contacted at random.

Table 3.4.1 Overview of sampling approach

	Wives	Daughters	Husbands	Sons	Total
Sample	42	29	36	11	118
Declined	4	4	2	6	16
Enrolled	7	7	7	5	26
Interviewed	**7**	**6**	**7**	**5**	**25**

In total, I enrolled seven wives, six daughters, seven husbands and five sons of people with dementia (see Table 3.3.1). Four wives, four daughters, two husbands and six sons of people with dementia declined their participation. Out of the nine carers who had initially contacted me to volunteer their participation, two men and two women were enrolled.

During the telephone follow-up I offered to visit carers in their own homes or at any other place of their convenience. Apart from one woman who I met in a pub of her choice, everyone preferred to be interviewed in their own home. This arrangement was chosen as I anticipated that it would reduce the burden on carers having to make care arrangements and remove transportation time. The interviews were conducted between July and September 2016. One interview scheduled with a daughter was not completed, as despite several attempts I was unable to meet the person.

Sample description

The analysis presented in Chapter 5 is based on 25 interviews with unpaid carers of people with dementia. The interviews were conducted with seven husbands, seven wives, six daughters and five sons of people with dementia and ranged in length from 23 minutes to four hours. They lasted 64 minutes on average.

When conducting the interviews, I thought that I would be able to obtain basic demographic information from the cohort database and so did not collect this information systematically. However, this turned out not to be possible. Therefore, description of the sample were based on estimates from the interviews with respect to dementia severity of the care recipient and carer age, where carers did not reveal their age voluntarily during the interview. The information based on estimates from the interview in Table 3.3.2 is marked with an asterisk.

Three of the daughters in this study looked after their fathers and three supported their mothers. The youngest daughter in the study was in her 50s/60s and the oldest in

her 70s. Only the youngest daughter was still in employment at the time of the interview. Three daughters explained having given up work early to support their parent with dementia. While all daughters had provided care for their parent in the community, three parents recently moved into care homes and one had passed away. One daughter and her family lived with her father, while another daughter's father had a live-in carer. One of the daughters supported parents with mild to moderate dementia and five daughters looked after parents with moderate to severe dementia.

All of the five sons interviewed for this study supported their mother with dementia. During the interviews with two of the sons, their wives were also present and contributed to the interview. The youngest son was in his 50s/60s and the oldest sons were in their 60s/70s. Four out of the five sons interviewed were retired at the time of the interview; however, one maintained links to his previous profession. Four of the mothers, as described above, lived in care homes. One mother, who also used to live in a care home, had recently passed away. One of the mothers lived with mild to moderate dementia, four with moderate to severe dementia.

The recent bereavement of parents with dementia among two of the filial carers may have affected their perspective. In both cases the parent with dementia had passed away several months before the interview. This may have allowed the filial carers to reflect on their care experience differently than family members involved in the day-to-day care. Bereavement among carers of people with dementia in the literature has been described as a grieving process in stages due to the experience of loss of the person with dementia through their progressive cognitive impairment (Gillies, 2011; Shuter, Beattie & Edwards, 2013). This may also have affected carers' willingness to participate in this study.

Among the seven wives interviewed, six cared for their husbands and one for her female civil partner. All wives supported their partners at home. The younger women were in their 60s and the oldest woman was in her 80s. Only Wife 1 was still in employment. One wife, similarly to three of the daughters, gave up working to care for her husband. Four of the women reported having moved within the last few years. Two of them moved to be closer to their daughters and two to live in more accessible housing. Five of the wives cared for partners with mild to moderate dementia, while one husband lived with moderate to severe dementia.

Similarly to the wives, all of the seven husbands interviewed supported their wives at home. The men were slightly older than the wives. The younger husbands were in their 70s or 80s. All of the husbands were retired; however, two retained active links

to their former profession. One husband reported that the couple recently moved into assisted living and one husband shared the house with his wife and their adult son, who also contributed to the care. Five of the husbands cared for wives with moderate to severe dementia; two husbands supported their wives with mild to moderate dementia. Overall husbands were older than wives and their partners lived with more advanced dementia.

Table 3.4.2 Overview characteristics of interviewees

Carer	**Care-recipient**	**Age**	**Employment**	**Cohabiting**	**Severity**
Daughter (1)	Father	60s	Retired	No	Moderate to severe*
Daughter (2)	Father	50/ 60s	Retired	Yes	Moderate to severe*
Daughter (3)	Father	50s/ 60s*	Retired	No	Mild to moderate*
Daughter (4)	Mother	50s/ 60s*	Working	No	Moderate to severe*
Daughter (5)	Mother	60s	Working	No	Moderate to severe*
Daughter (6)	Mother	70s	Retired	No	Moderate to severe*
Son (1)	Mother	60s/ 70s*	Retired	No	Moderate to severe*
Son/ Daughter in law (2)	Mothers	60s/ 70s*	Retired	No	Moderate to severe*
Son/ Daughter in law (3)	Mother	60s	Retired	No	Moderate to severe*
Son (4)	Mother	50s /60s*	Employed	No	Mild to moderate**
Son (5)	Mother	60s/ 70s*	Retired	No	Moderate to severe*
Wife (1)	Husband	60s	Employed	Yes	Mild to moderate*
Wife (2)	Husband	80s	Retired	Yes	Mild to moderate*
Wife (3)	Husband	60s* /70s	Retired	Yes	Mild to moderate*
Wife (4)	Husband	80s	Retired	Yes	Mild to moderate*
Wife (5)	Civil partner	70s	Retired	Yes	Mild to moderate*
Wife (6)	Husband	60s	Retired	Yes	Moderate-severe*
Wife (7)	Husband	60s	Retired	Yes	Mild to moderate*
Husband (1)	Wife	70s/ 80*	Retired	Yes	Moderate to severe*
Husband (2)	Wife	70s/ 80s*	Retired	Yes	Moderate to severe*
Husband (3)	Wife	80s	Retired	Yes	Mild to moderate*

**estimated from interview*

Carer	Care-recipient	Age	Employment	Cohabiting	Severity
Husband (4)	Wife	70s	Retired	Yes	Mild to moderate*
Husband (5)	Wife	70s/ 80s*	Retired	Yes	Moderate to severe*
Husband (6)	Wife	70s/ 80s*	Retired	Yes	Moderate to severe*
Husband (7)	Wife	70s/ 80s*	Retired	Yes	Moderate to severe*

**estimated from interview*

3.4.2 Questions explored

The qualitative interviews aimed to explore how carers constructed carer well-being based on their personal experience of looking after a relative with dementia. The interviews were structured in a similar fashion, using a topic guide (Appendix 1). The guide was followed in all interviews, but order and extent to which questions were explored varied to allow in-depth exploration of related topics carers mentioned. This approach ensured a systematic approach, while also enabling me to explore other, related topic areas carers brought up. The topic guide consisted of two main parts. First, carers' personal background and their individual care experiences were explored. Then carers' thoughts on their understanding of well-being and their perceptions of the role of gender and age in dementia care were investigated.

The interviews started with opening questions eliciting the respondent's background and then moved on to explore their care experience. Carers often described the situation of their care-recipient and reflected on their and their relatives' lives and contrasted these with their lives before their relative with dementia developed care needs. These introductory questions helped me to get an understanding of how the person I interviewed viewed their current life situation. As outlined in Section 3.2, critical realism understands that people interpret reality based on acquired social norms. Awareness of how people portrayed their past and current experiences built an important base for my analysis of how carers conceptualised well-being and their perceptions on the impact of age and gender on their role as carers. In addition, starting the interview with questions about their experience as a carer also helped interviewees to build trust in me as their interview partner.

After exploring carers' personal experiences, I lifted the interview to a more abstract level. With the help of the topic guide, the interviewee and I explored participants' perceptions on what it means to be a carer as a man or woman of a certain age and in the role of a spouse or filial carer. We also explored of what carers understood by the term well-being and if or how this understanding changed since they took on their carer role. When exploring the prisms of age and gender, I was particularly interested in understanding whether carers identified their role as conforming with social norms or whether they felt social pressure to fulfil a certain role. Two daughters, for instance, reported the social and parental pressure they felt to take on care responsibility. Some husbands, on the other hand, described how they left their traditional male breadwinner role and entered a new role, which in some cases included

supporting their wives in putting on make-up (see Chapter 5).

From exploring these aspects, I moved the interviews to carers' perceptions on well-being. After carers provided their own definition of well-being or where they described how a 'good day' differed from a 'bad day', we also explored aspects that could affect their well-being, such as isolation, loneliness and the potential experience of financial implications as a result of caregiving. I found it important to explore these components in the context of well-being, as carers might otherwise not report on these underlying aspects, as they could be associated with social stigma.

During interviews with spouse carers we also spoke about whether the dementia had affected their intimate or sexual relationship and how this affected their wellbeing. I added this question following the recommendation from the MODEM reference group. The reference group is a group of people with dementia and carers advising the MODEM research project. Due to my association with the MODEM project I was able to present the initial study outline and topic guide to this group and benefit from their feedback.

Before closing the interview, I used a question asking the carer for their advice to people new to their caring role to wind down the conversation from an abstract level to a more positive, constructive outlook focusing on the carer's experience and expertise. Finally, I gave carers the opportunity to raise any other points they wanted to mention. At this point, none of the carers returned to the substantive part of the interview, which suggested to me that carers had been given the chance to express their views during the interview process. Instead, some carers asked questions about my motivation for engaging in this research.

3.4.3 Ethical reflections

In the preparation of and during the interviews a number of potential ethical issues were considered to ensure that both participants and research could mutually benefit from this study. When focusing on the well-being of unpaid carers, it needed to be anticipated that the well-being of carers and care-recipients were closely linked. Even though the focus of this research was on the experience of the carer, the importance of the relationship with the care-recipient, the feelings of the carer towards the care-recipients and towards the care situation meant that all carers spoke to me about the person with dementia. Many carers wanted me to understand the difference between the person they now care for and the parent or partner they used to be. Making me understand what their relative with dementia and they as partner or adult child, had lost was very important to

their own experience and well-being. As I was interested in the carer's account, I decided not to include the care-recipient in the interview process. However, this raised ethical issues around pursuing research that includes the situation of people with dementia without giving them a voice (Nygard, 2006). For this reason, I encouraged carers in the introduction letter and during the follow-up phone call to discuss their participation in the study with the person with dementia where possible, and to include the person with dementia in the decision-making process on whether or not to engage in this study.

Some spouses wanted me to meet their partner with dementia and on several occasions I would have a chat with both carer and care-recipient before or after the interview. Whenever this was the case, the spouses introduced me in my role as a researcher. I found that while spouses appreciated being able to talk freely about their experience and feelings, they also validated being seen as a couple. The spouses with dementia, in turn, seemed to appreciate meeting the person their spouse had spoken to and to be recognised as an individual.

A further ethical issue was the risk that carers might experience their participation in this study as an intrusion into their personal lives and that talking about their personal experience could become emotionally overwhelming. The personal nature of these questions, covering grounds such as support from family and friends, feelings of loneliness, physical and mental health, self-esteem, financial implication and the intimate relationship between carer and care-recipient, could have caused discomfort and distress. I aimed to minimise this risk by informing the respondent about the purpose and topics I aimed to discuss ahead of the interview.

Some carers seemed to find having knowledge about the topics I was planning to explore helpful in their decision-making as to whether or not to participate, but also in preparing themselves emotionally for the topics that we discussed. I noticed that a couple of carers had prepared notes on aspects they wanted to discuss. It also became clear in situations, where during the interview carers directed me towards specific topic areas they particularly wanted to talk about.

In situations where carers got a bit upset during the interview, I offered taking a break. However, none of the participants took up on this offer. On the contrary, carers appeared keen to speak about their experiences even if they brought back negative or painful emotions and memories. Furthermore, as I started the interviews I emphasised that participants could always tell me should they not want to answer a particular

question or prefer to terminate the interview. On one occasion, a carer wanted to emphasise a point by comparing his or her own case to that of another person. This carer asked me to switch off the recording device while they told me about this other case as they felt including other people's experience without their knowledge of it being used for research was inappropriate. This request was naturally respected and the carer told me when I was allowed to turn the recording devices on again. Furthermore, two men reported after the interview that speaking about their feelings on this matter was new to them, but that they found it to be a positive experience.

3.4.4 Data analysis

Two professional transcribers and myself transcribed the audio-recorded interviews. Following the transcription, I anonymised the verbatim transcripts by removing the names of the interviewees, the person with dementia, of other people, but also of places and organisations mentioned during the interview. I decided to remove these personal identifiers to protect people's identities and because the focus of the analysis was on the narrative. I did not view people's names, the exact name of places they referred to or the names of specific organisations they engaged with as imperative to the overall narrative.

Similarly, the field notes, in which I noted the thoughts and impressions I had after the interview, did not contain any direct personal identifiers. These field notes and the verbatim transcripts built the basis of the analysis.

Thematic analysis, a method to systematically analyse patterns in qualitative data by coding similar observations or shared meaning under relevant themes, was used to analyse the data (Guest, MacQueen & Namey, 2012; Boyatzis, 1998; Ritchie et al., 2014). As outlined in Section 3.2, I analysed the data using a critical realist approach. Furthermore, I used an iterative approach initially, developing codes inductively to explore the breadth of themes related to the concept of well-being, and later a deductive approach to compare and contrast data with the themes identified in the review of well-being and quality of life studies presented in Chapter 2 (Hennink, Hutter, Bailey, 2011, p.246; Boyatzis, 1998).

First, I read the transcribed material repeatedly for the purpose of keyword finding and familiarisation with the data. Then, as interviews were conducted following a semi-structured guide, I identified the section in each interview where carers outlined their definition of well-being or what it meant to be well for them so it could easily be identified and analysed. This allowed me to get an initial idea of aspects that carers deemed important to their well-being. I identified fourteen aspects: the absence of

financial concerns, being allowed to show weakness, receiving attention and being looked after, experiencing happy moments and feelings of optimism, an overall positive state of mind, feeling empowered, physical components, having a network and place to relax, time for oneself and the ability to pursue own interests, eating well, getting a good night's sleep, peace of mind, security and experiencing being loved and loving. These components built the initial codebook.

Next, I systematically analysed line-by-line focusing on aspects influencing carer well-being. Where data fitted with initial codes identified in carer definition of well-being they were added to this classification. Where new components emerged, these were coded separately.

In another step I revisited each of the initial codes and, where I found conceptual overlap, I grouped them into larger, more abstract themes (Ritchie et al., 2014). For instance carer health, identified in the initial coding, remained one of the key themes influencing carer well-being, while the initial codes 'time for self' and 'pursuing one's interests' were absorbed into the larger concept of coping mechanisms. I also gave considerable thought to observations inconsistent with findings across the data or the literature. One carer, for instance, appeared to want to challenge me with some statements. This person repeatedly asked whether the views they expressed would shock me. Analysing this person's account required me to step back and to reflect on these remarks by taking into consideration the person's other life circumstances and experiences they revealed to me.

The two-step process, looking first at carers' definitions of well-being and then focusing on the narrative based on their personal experience, enabled me to compare and contrast between the aspects initially mentioned and the themes that emerged from the wider narrative. For example, the aspect 'eating well' mentioned in one person's response to the question what well-being means to them, was not picked up on again in any of the interviews.

Finally, the six key themes remained: 'the relationship with the care-recipient', 'support from family and friends', 'safety and security of the person with dementia', 'successful use of coping mechanisms', 'external facilitators to well-being' and 'carer health'. The component 'relationships with the care-recipient', for instance, brings together topics such as carer reflections on the relationship prior to dementia, intimacy and sexual relationship, the carers need to protect their partners role, feelings of reciprocity, hurtful experiences and the handling of challenging behaviour. A

conceptual framework, explaining how these different aspects 'hang together', can be found in Chapter 5.2. I also analysed the six components and possible determinants of well-being for each of the four carer groups and compared and contrasted differences and similarities between them. The results can be found in Chapter 5.3. Data analysis was performed using QCR NVivo software.

The data presented in Chapter 5 ties the quotes to the carer characteristics outlined in Section 3.4.1. This was done for the examination process following a conversation with my supervisors and will be further anonymised for publication to reduce the possibility of identification.

3.4.5 Reflections

Despite using a sampling approach that aimed to reduce self-selection bias, some carers had previously been involved in qualitative research. This may have meant that these participants were repeating a narrative previously developed. In addition, some carers, who previously had engaged in qualitative research almost seemed to have an agenda of items they wished to bring across. However, the semi-structured nature of the interview meant that in all interviews, it was possible to explore the carer's understanding of well-being and their perception of their role as a man or a woman of a certain age and in relationship to the person they cared for. Exploring these concepts in the context of care seemed new to all carers.

When planning the interviews it was pointed out to me that not being a native English speaker could pose challenges in conducting qualitative interviews, especially where carers may use idioms or compare their understanding to cultural programmes that I might be unaware of. When conducting the interviews, several carers picked up on my accent.

However, instead of this becoming a problem I found myself in a situation where participants wanted to make sure that I understood what they meant and it enabled me to easily ask for clarifications.

Conducting interviews with carers of people with dementia who were all older than me may have affected the discourse. While many of the men seemed not to have difficulties expressing their thoughts and feelings in front of me, perhaps because my situation was so different to theirs, this may have been different for some women. A couple of women expressed the preference to talk to women of their age about their experience, as they felt they could understand their situation better. While this was

mentioned not with respect to this interview, my age might have affected the way in which some participants responded to me.

3.5 Carer well-being over time

This section outlines the underlying methodological and analytical approaches employed in Chapter 6. The research question explored is: 'How do well-being and quality of life of male and female carers of people with dementia of different age change over time?' Data are analysed using regression analysis.

3.5.1 Measuring carer well-being and quality of life

As discussed in Chapter 2, there are conceptual differences between well-being and quality of life measures, even though there appears to be little consensus on how to measure well-being. Carer health-related quality of life in this analysis was measured using the commonly used EQ-5D (see Chapter 2.3.2). This variable was available in the three datasets MODEM, START and SHIELD-CSP-RYCT. Choosing appropriate measures to estimate carer well-being was more difficult, as none of the datasets specifically was collected for this purpose.

Given the importance of mental health to carer well-being in the literature, the HADS depression scale measuring carer depression, which was available in both START and SHIELD-CSP-RYCT, was used. This scale had been used in two of the well-being studies identified in the literature review (Ask et al., 2014; Charlesworth et al., 2008). START further collected the HSQ-12. One of the questions in this questionnaire ('Have you been happy?) was used in isolation to measure hedonic well-being. In SHIELD-CSP-RYCT the Personal Growth Index (PGI) had been collected. While this measure was not identified in the literature review presented in Chapter 2, the concept of personal growth reflects eudaimonic well-being and was also identified as one of the components contributing to psychological well-being (Ryff, 2014). In MODEM, the General Health Questionnaire (GHQ-12) was available to measure carer mental health. This measure had been used by two studies in the literature to estimate carer well-being (Schoenmakers, Buntinx & DeLepeleire, 2010a; Coen et al., 1999). Furthermore, in Wave II of the MODEM cohort study we collected the ONS personal well-being questions (see Chapter 2.1). As outlined in Chapter 2, these four questions measure aspects of both hedonic and eudaimonic well-being.

Table 3.5.1 Overview of outcome variables used in START, SHIELD-CSP-RYCT and MODEM

	START	SHIELD-CSP-RYCT	MODEM
Quality of life			
EQ-5D	X	X	X
Well-being			
HADS D	X	X	
HSQ12	X		
PGI		X	
GHQ			X
Personal Well-being Scale			X

Outcome variable measuring carer quality of life

The **EQ-5D** captured respondent health status in the five dimensions 'mobility, self-care, usual activities, pain, discomfort and anxiety/depression'. There were two versions available offering either 3 or 5 levels for each dimensions. The EQ-5D-3L contains 3 response options: 'no problems, some problems and extreme problems' (EuroQol Group, 2015a). This version was used in START and MODEM. The EQ-5D-5L contained 5 response options: 'no problems, slight problems, moderate problems, severe problems and extreme problems' (EuroQol Group, 2015b). This version was used in SHIELD-CSP-RYCT. In both versions, higher scores mean better health-related quality of life.

Outcome variables measuring carer well-being

The Hospital and Anxiety Depression Scale (HADS), as shown in Chapter 2, was used as primary outcome variable in two studies measuring carer well-being (Ask et al., 2014; Charlesworth et al., 2008). Both START and SHIELD-CSP-RYCT collected the HADS. Initially developed by Zigmond and Snaith (1983, p.361) to enhance the 'detection and management of emotional disorder in patients […] in medical and surgical departments' the measure distinguishes in its collection between seven questions targeting anxiety and seven questions focusing on dementia. The scale has been validated for people of all ages and for people with or without physical problems (Bjelland et al., 2002).

Frequently the two subscales are analysed separately. In this analysis I focused on the depression scale. While I have criticised the oversimplification of measuring well-being through the absence of depression and anxiety in Chapter 2, mental health clearly plays an important role in the well-being of carers. Furthermore, looking more closely at the statements through which the HADS depression scale is assessed, it shows a clear conceptual proximity with hedonic well-being. Examples include 'I still enjoy the things I used to enjoy', 'I can laugh and see the funny side of things', 'I feel cheerful', 'I look forward to enjoyment with things' and 'I can enjoy a good book or radio or TV programme'. Higher scores reflect the experience of more depressive symptoms.

In START, the 12-item **Caregiver Health Status Questionnaire (HSQ)** was available. While the overall questionnaire aims to measure health-related quality of life, one of the components asks 'have you been a happy person?' (Livingston, 2014a). In the absence of other specific well-being measures in START, this component score was used in isolation to measure hedonic well-being of carers. Lower scores reflect greater happiness.

The **Personal Growth Index (PGI)** was collected in SHIELD-CSP-RYCT (Charlesworth et al., 2011; Ryff & Keyes, 1995). The three-item measure includes the questions 'For me, life has been a continuous process of learning, changing and growth', 'I gave up trying to make big improvement or changes in my life a long time ago' and 'I think it is important to have new experiences that challenge how I think about myself and the world'. This three-item measure focuses on eudaimonic well-being and was therefore included in this analysis. The measure used a positive rating, which means that higher scores indicate greater personal growth.

In the MODEM cohort study **the General Health Questionnaire (GHQ-12)** was available (Goldberg, 1992). This widely used instrument measures general psychological health (Molina, 2014) and had previously been used to estimate carer well-being (Schoenmakers, Buntinx & DeLepeleire, 2010b; Coen et al., 1999). The inclusion of questions, such as 'Have you recently felt that you are playing a useful part in things?' and 'Have you recently been feeling reasonably happy, all things considered?' indicate its relevance as a well-being proxy-measure. Lower scores indicate greater well-being.

The MODEM cohort study further collected information on carer well-being through the **Personal Well-being Scale**. The scale, developed by the Office for National Statistics, has been used to gather information about people's subjective well-

being collected as part of the Annual Population Survey (APS) since April 2011 (ONS, 2012). The four questions are: 'Overall, how satisfied are you with life nowadays?' 'Overall, to what extent do you feel that the things you do in your life are worthwhile?', 'Overall, how happy did you feel yesterday?' and 'On a scale, where nought is 'not at all anxious' and 10 is 'completely anxious', overall, how anxious did you feel yesterday?'. The first three measures are coded positively, meaning that higher values indicate greater well-being. The fourth question represents less anxiety with greater values.

We added this measure as part of the second wave of data collection in recognition of the importance of carer well-being and for the purpose of comparing between the personal well-being of carers with people in the general population. This means, however, that there are no baseline values available for these variables.

Independent variables informing carer quality of life and well-being in START, SHIELD-CSP-RYCT and MODEM

The framework presented in Chapter 2 informed the choice of independent variables considered for this research. The variables available in the three datasets MODEM, START and SHIELD-CSP-RYCT were compared to the earlier framework and suitable variables were identified. These include carer characteristics such as gender, age, marital status, education and employment. Ethnic origin of participants was not included as the three datasets collected information on predominantly white-British participants (see Chapter 4, Table 4.1). The MODEM data, in addition, collected information on whether the carer provided unpaid care to other people in their network.

Other variables provided information on the experience of carer burden using the Zarit burden inventory (START, MODEM), the ways in which carers cope with the demands placed upon them (COPE inventory available in START and SHIELD-CSP-RYCT) and about carers' physical and mental health (e.g. the short-form-12 questionnaire collected in SHIELD-CSP-RYCT, MODEM). START and MODEM datasets further contained information on carers' use of counselling, hospital services (START) and community services (MODEM).

Other less common measures available included information on carers' sleep (MODEM) and caregiving self-efficacy (SHIELD-CSP-RYCT). Potentially abusive behaviour by the carer was measured in START with the help of the Modified Conflict Tactics Scale (MCTS) (Cooper et al., 2009). Furthermore, MODEM provided information on social resources available to the carer using the Older American

Resources and Services (OARS) Social Resources Scale (Fillenbaum, 1998). SHIELD-CSP-RYCT collected information on carer loneliness (Stroebe et al., 1996).

In addition, variables in all three datasets offer insights on the care dyad, such as the relationship between carer and care-recipient, whether they live together, and whether other carers support the person with dementia. The three studies further collected information on the time that co-resident carers can leave the care-recipients alone. All three datasets also provided a number of variables containing information about the care-recipient. The three studies consistently collected care-recipient information, such as age and gender and dementia severity (using the Clinical Dementia Rating (CDR) and/or the Mini-Mental-State Examination) (Hughes et al., 1985; Folstein, Folstein & McHugh, 1995).

A dementia-specific quality of life measure can be found in START and SHIELD-CSP-RYCT. The Quality of Life – Alzheimer's Disease Scale (QoL-AD) measures quality of life of the care-recipient (Logsdon et al., 2002; Charlesworth et al., 2011; Livingston et al., 2014b). The responses to this measure, however, were provided by the carer. START, SHIELD-CSP-RYCT and MODEM further provided detailed information on care-recipients' receipt of services and benefits, such the use of day care, social services, other types of community support and the receipt of benefits. In addition, there was information on the medical support provided to people with dementia. These services included hospitalisation, community mental health services and medical services in the community. Furthermore, the level of dependency of the person with dementia was measured in SHIELD-CSP-RYCT using the Alzheimer's Disease Cooperative Study – Activities of Daily Living Inventory (ADCS-ADL) (Galasko et al., 1997; Bucks et al., 1996). The measure is concerned with establishing the degree of support care-recipients required with the completion of everyday activities. Finally, the Neuropsychiatric Inventory, providing information on care-recipient behaviour as rated by the carer, was available in all three studies using (Cummings et al., 1994).

Table 3.5.2 Overview of independent variables

	START	SHIELD-CSP-RYCT	MODEM
Carer			
Gender	X	X	X
Age	X	X	X
Marital status	X	X	X
Education	X	X	X
Employment	X	X	X
Financial implications	X		X
Receipt of carer allowance			X
Other care-recipients			X
Zarit Burden	X		X
Cope Inventory	X	X	
Health	Self-rated	SF-12	SF-12 Self-rated Chronic illness Health affected due to care responsibility
Counselling	X		X
Use of hospital services	X		
Community support			X
Sleep-disruption due to care needs			X
Caregiving Self-Efficacy		RSSE	
Managing behaviour	MCTS		
Social resources			OARS
Loneliness		X	
Carer dyad			
Relationship	X	X	X
Co-residence	X	X	X
Other carers	X	X	X
Time care-recipient can be left alone	X	X	X
Care-recipient			
Age	X	X	X
Gender	X	X	X
QoL-AD	X	X	
Severity	CDR/ MMSE	CDR/MMSE	MMSE
Daycare	X		X
Social services	X		
Community support			X
Benefits	X		
Hospitalisation	X		X
Community mental health services	X		
Medical services in the community			X
Dependency		ADCS	
NPI	X	X	X

3.5.2 Data analysis

In the following I describe how the datasets START, SHIELD-CSP-RYCT and MODEM were analysed individually using regression analysis to explore carer well-being and quality of life over time.

First, univariate regression analyses between the different outcome and independent variables available in the three datasets (and described above) were performed using the 12-month score of the outcome variable and the different independent variables at baseline.

Univariate regression analysis algebraically is denoted as:

$$E(Y|X) = \alpha + \beta X_i + \varepsilon_i$$

Independent variables that showed a statistically significant association with the different outcome variables were then considered for multiple regression analysis.

$$E(Y|X) = \alpha + \beta_1 X_1 + \beta_2 X_2 + \ldots + \varepsilon_i$$

Hence for EQ-5D: $\text{EQ-5D}_{12m\,i} = \alpha + \beta_1 X_{1i} + \beta_2\ \text{EQ-5D}_{baseline} + \ldots + \beta_k Xk_i + \varepsilon_i$

To satisfy the assumptions of multiple regression analysis, observations of Y_i need to be statistically independent of each other. Furthermore, observations Y_i have to be randomly sampled from a population in which Y_i exhibits a normal distribution with mean μ_i and variance σ^2. The assumption of homoscedacity requires that variance σ^2 is equal for all units *i* and independent of X_i.

Furthermore, it is also required that 'the mean μ of Y_i for each unit *i'* is associated with 'the value of the explanatory variables X_{1i}, $X_{2i,}$,… X_{ki} through the linear function'

$$\mu_i = \alpha + \beta_1 X_{1i} + \beta_2 X_{2i} + \ldots + \beta_k X_{ki}$$

with α and $\beta_1, \beta_2, \ldots, \beta_k$ representing unknown population parameters. In addition, all error terms 'ε_i are statistically independent of each other' (Kuha & Lauderdale, 2014/2015, pp.53-54). The mean error term ε_i is expected to be 0 for all *i* independent of $X_{1i}, X_{2i}, \ldots, X_{ki.}$ Also the variance of the error term ε_i is σ^2 for all *i* and independent of $X_{1i}, X_{2i}, \ldots, X_{ki.}$ (Kuha & Lauderdale, 2014/2015).

Before the models could be built, the outcome variable was investigated to ensure that it was normally distributed. Where this was not the case, transformations of the outcome variables were explored. Then univariate analyses between each of the outcome variables and the pre-selected independent variables considered for this analysis were conducted to explore initial associations. In a next step, consistent with the approach taken in Chapter 7 (see Chapter 3.6.3), multiple regression models were built for each of the outcome variables exploring the following carer and care-recipient

characteristics: carer gender and age, relationship to the care-recipient, co-residence with the care-recipient, dementia severity of the care-recipient as well as age and gender of the care-recipient. In addition, the baseline measure of the outcome variable and a dummy variable representing the carers' allocation to intervention or control arm, where appropriate, were included in the models. For each model, the coefficient of determination (r^2), the Akaike information criterion (AIC), and residual plots were recorded (Akaike, 1974). The models investigating only carer and care-recipient characteristics were built to enable comparison with the models exploring the independent variables that showed a significant association in the univariate analysis described below and can be found in Appendix 5.

The final multiple regression models for the 12-month outcome scores were built using a stepwise, forward selection approach. Each model was started by introducing carer age and gender as independent variables. In the analysis of the trial datasets START and SHIELD-CSP-RYCT a dummy variable indicating carer enrolment into the treatment or control arm was introduced in each model as well. In addition, for all outcome variables apart from the four personal well-being measures investigated using the MODEM dataset where no baseline scores were available, baseline values of the outcome variable were introduced as independent variables.

Next, the carer and care-recipient characteristics explored in the first model as well as the variables that indicated a significant association from the univariate analyses were introduced to the model one at a time. After the introduction of an independent variable to the model, a link test was performed to see whether the model was 'specified correctly' (STATA, 2014). In addition, the AIC was established to determine whether the additional variable improved the model. The AIC indicates model improvement when the value diminishes. Where the model was improved by the additional variable, it remained in the model. Where a variable did not contribute to an improvement of the model, it was removed.

Multiple regression analysis always bears the risk of multicollinearity. In order to prevent interactions between variables being overshadowed by other variables with which they are highly correlated, I tested the independent variables for strengths of association. Associations between continuous variables were assessed using the Pearson correlation coefficient, categorical variables were investigated using Pearson's chi-squared tests and t-tests were used to look at the strength of relationships between continuous and categorical variables. In situations where the introduction of a variable

led to multicollinearity, I first investigated the model including all variables in question to see whether previously observed effects were overridden. Next, I removed the variable that previously was in the model and had the strongest association with the newly introduced independent variable. Then I compared the AIC and the coefficient of determination (r^2) of the model prior to the introduction of the new variable with the model including the new variable but not the most strongly correlated variable to determine which model was better. The better model was then carried forward.

Carer age and gender were the focus in this thesis and therefore included in all models from the beginning, even if no statistically significant association was found with the outcome variable in the univariate analysis or the first model investigating carer characteristics. The final model was achieved when all relevant independent variables had been introduced and their contribution through the AIC determined.

Following imputation of the datasets START and MODEM (described below, see Section 3.5.3), the full-stepwise approach described above was completed using a randomly picked imputation. The three best models were then compared across five other randomly picked imputations. When the best model was consistently identified across imputations using the AIC, this model was chosen as the best and was run using the multiple imputations command. Where differences occurred, the full stepwise approach was performed across the five other imputations to identify where the difference occurred (White, Royston & Wood, 2011). A decision was made on which model was best for most of the imputations.

Since no gold-standard post-estimation techniques for regression analysis using imputed data exist, residuals were investigated following each of the models. For the imputed models, residuals of the initial non-imputed dataset (Imputation 0) were compared with the residuals of two randomly picked imputations (Imputation 4 & imputation 15). For consistency, the same approach was used in the case analyses. Where the residuals did not indicate any problems with regards to distribution of the data, heteroscedasticity, non-linearity or extreme outliers, the models were accepted. Where problems were observed, I adopted traditional approaches of exploring whether transformation of the dependent variable or the identification of outliers could improve the residual plots. The data was analysed using STATA 14.

3.5.3 Imputation

Missing data in both the START and MODEM datasets at 12-months follow-up would lead to analysis with less statistical power and lower representativeness of the population. To counteract this problem, multiple imputations were performed for START and MODEM. SHIELD-CSP-RYCT was received by me in an imputed format, and the imputation procedures have been published elsewhere (Charlesworth et al., 2016).

Before data can be imputed it is important to determine whether missing values occur at random. In some cases, data can be related to other variables in the dataset. For example, where individual income is particularly high or low it could be that people would not want to disclose this information. If missing data is not related to its own value or other variables collected in the datasets, data is considered to be 'missing completely at random' (MCAR). Since the value of the missing data is unknown and only a limited number of potentially related variables can be tested in most datasets, it is a very strong assumption to conclude that data is missing completely at random.

Data missing completely at random (MCAR)

$$P(R|Y,X,W)=P(R)$$

A second, less strong assumption taken can be that data is 'missing at random (MAR)'. This means that while missingness may depend on other variables, the values do not. Income and education, for instance, are likely to be related. However, among people with the same level of education, the likelihood of reporting their income is not associated with their individual amount of income (Byrne, 2001; King, 2010).

Data missing at random (MAR)

$$P(R|Y,X,W)=P(R|Y^{o}, X, W)$$

If it were the case that people with the same educational qualifications with higher or lower income would be less willing to state their individual income this would be considered as 'data not missing at random' (NMAR).

An important limitation of MAR is that, using the above example, variables that could determine missingness may not be collected as part of the dataset. An example could be a measure of pride. If people of a particular educational group may have comparatively low income, respondents may choose not to declare their income out of embarrassment. If pride has not been collected it would be impossible proving that data was not missing at random and instead MAR could be assumed.

While there are different ways of treating missing data, such as listwise deletion for MCAR data or predicting missing data through the mean of observed data where data is MAR, in this thesis missing data will be handled by using multiple imputation by chained equations (Scheffer, 2002; King, 2010). Multiple imputation estimates 'likely values' for the missing data based on the observed data, creating multiple plausible 'versions of the complete data set' (White, Royston & Wood, 2011, p.377; King, 2010, p.61; Wulff & Ejlskov, 2017, p.42).

Following Rubin's (1987) rule for scalar estimates, the different datasets were analysed separately and their results combined. Multiple imputations contain 'uncertainty around imputed values' and maintain 'the variance structure of the data' (King, 2010, p.61).

According to Rubin (1996)

$$\left(1+\frac{\gamma}{m}\right)^{-1/2}$$

approximates 'the relative efficiency of an estimate based on the number of imputations' (King, 2010, p.62). γ denotes 'the rate of missing information for the quantity being estimated' and *m* the number of imputations. Standard deviations are the unit of measurement for efficiency (King, 2010, p.62).

The combined estimate θ is 'the average of the individual estimates' and incorporates both within- and between- imputation variability (White, Royston & Wood, 2011, p.378).

It is denoted as:

$$\hat{\theta}=\frac{1}{m}\sum_{j=1}^{m}\hat{\theta}_j$$

The total variance of θ is derived from the within-imputation variance,

where W is the estimated variance of θ_i : $\mathbf{W}=\left(\frac{1}{m}\right)\sum_{j=1}^{m}\mathrm{W}_j$

and the between-imputation variance: $\mathbf{B}=\left(\frac{1}{(m-1)}\right)\sum_{j=1}^{m}\left(\hat{\theta}_j-\hat{\theta}\right)^2$

and denoted as: $\mathrm{var}\left(\hat{\theta}\right)=\mathbf{W}+\left(1+\frac{1}{m}\right)\mathbf{B}$. (White, Royston & Wood, 2011, p.378).

Multiple imputation by chained equations has the unique ability to deal with different variable types (continuous, binary or ordered categorical) as each variable 'is imputed using its own imputation model' (White, Royston & Wood, 2011, p.378). The process fills missing values with plausible values by regressing a variable with missing values, x_1, on all other variables in the model $x_2,\ldots,x_k$ that contain observed values for

x_1. This cycle is then repeated for all other registered variables with imputed values. The process is then repeated several times to stabilise the values and results in one single imputation (White, Royston & Wood, 2011, p.378). Before the imputation process, the number of imputations is determined, and the process will be repeated until *m* imputations are calculated. White, Royston and Wood (2011, p.388) suggest that '*m* should be at least equal to the percentage of incomplete cases'. As suggested above, the strength of multiple imputations by chained equations is that it can take account of the type of variable *z*, whose missing values will be imputed from other complete variables $\mathbf{x}=(x_1,\ldots,x_k)$.

For normally distributed variables, linear regression models were used

$$z|\mathbf{x};\ \beta \sim \mathrm{N}(\beta\mathbf{x}, \sigma^2).$$

For binary variables, logistic regression models were applied.

$$\mathrm{logit}\,\Pr(z = 1|\mathbf{x};\ \beta) = \beta\mathbf{x}.$$

And for ordered categorical variables ordered logistic regression models were used.

$$\mathrm{logit}\,\Pr(z \leq l|\mathbf{x};\ \beta, \zeta) = \zeta_l - \beta\mathbf{x}.$$

(see White, Royston & Wood, 2011, pp.379-380).

In the literature it has been acknowledged that introducing auxiliary variables that are not used for the analysis can improve the imputed values. Auxiliary variables are variables in the original dataset that are not included in the analysis, but are correlated with the variables of interest or help to keep the missing process at random (Hardt, Herke & Leonhart, 2012). This was explored in the imputation models for START and MODEM and described in greater detail in Sections 6.3.2 and 6.5.2. Furthermore, an effort has been made to include predictors that both 'predict the incomplete variable' and 'whether the incomplete variable is missing' (White, Royston & Wood, 2011, p.384).

3.6 Time commitment to care

This section describes the methodological and analytical approaches of results employed in Chapter 7. The research question explored is: 'What factors influence the time commitment of different tasks by men and women of different ages caring for a relative with dementia?' Cross-sectional negative binomial regression models were used for this analysis.

3.6.1 The development of the amended Resource Utilization in Dementia (RUD) measure

As described in Section 3.2.1, the association of my studentship with the MODEM project enabled me to contribute to the development of questions included in the cohort study. One of the most frequently used measures to estimate the amount of time spent on caring by carers of people with dementia is the Resource Utilization in Dementia (RUD) questionnaire and it is commonly used to estimate unpaid care cost. Time spent caring has also been found to be associated with carer well-being and quality of life (Joling et al., 2015; Chappell & Reid, 2002; Serrano-Aguilar, Lopez-Bastida, J. & Yanes-Lopez, V., 2006). However, little attention has been paid to factors influencing time spent caring. This aspect was explored cross-sectionally in this research and its results are presented in Chapter 7. Below I outline how an amended version was developed for the MODEM cohort study.

The RUD questionnaire initially was developed by Anders Wimo and colleagues in 1998 (Wimo et al., 2013a). Since its development, the RUD has been used in a number of countries, such as France, Ireland and China (Gervès, Chauvin & Bellanger, 2014; Yan et al., 2014). So far only one study is known to have collected the RUD in the UK (Lenox-Smith et al., 2016; Haro et al., 2014). This data collection, however, was part of a larger European comparative project and did not specifically focus on factors influencing time carers spend supporting a person with dementia.

The RUD collects information on the time carers spend on Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs) and supervision. The questionnaire offers a number of examples of ADLs, such as assisting with eating, dressing, grooming, walking, bathing or using the toilet, and IADLs, including tasks such as support with 'shopping, food preparation, housekeeping, laundry, transportation, taking medication' and financial matters (Wimo et al, 2013a, pp.435.e2-435.e9). Carers are then asked how much time in total they spend on ADL and IADL activities. The concept of supervision is

framed more generally; describing supervision as time spent 'preventing dangerous events' (Wimo et al, 2013a, pp.435.e2-435.e9).

In 2012, Bellanger and colleagues amended the RUD questionnaire to collect information on the time carers spend on each of the different ADL and IADL tasks outlined above. Carers were asked specifically how much time they spent on helping the person they support with toileting, dressing and undressing, nutrition, moving around, helping with looking after one self, the household, transportation, finances or medication.

When developing the questionnaire for the MODEM cohort study, with the approval of Anders Wimo and Martine Bellanger, we amended the initial RUD in line with the French study. This allowed us to explore the different ADL and IADL tasks separately. The question on supervision remained unchanged from the initial study. We decided to pursue this approach as it could provide insights on tasks that carers experience as particularly time-consuming, but also to see whether there is variation in tasks for different carer and care-recipient groups. The descriptive analysis presented in Chapter 7.1 explores some aspects of this.

One important aspect that the RUD so far had not captured, but that developers since have considered, is that dementia care often involves more than one carer (unpaid and/or paid) (Wimo et al, 2013a, p.432). For this reason, we did not just elicit information on how much time the interviewed carer spends on ADL, IADL and supervision tasks, but also explored how much time *other* unpaid and paid carers, if there were any, spend on each of the care tasks. All of this information was provided by the interviewed carer. In a similar German study, Neubauer and colleagues (2008, p.1160) found that total care time would have been underestimated by 14% if carers other than the primary carer had not been considered in the analysis. The amended RUD questionnaire used in the MODEM cohort study can be found in Appendix 6.1.

3.6.2 The five outcome variables investigating aspects of time spent on dementia care

In order to investigate aspects influencing the time that carers of people with dementia spend on the different care tasks outlined above, five models were developed: one model focuses on time spent on ADL tasks, one on IADL tasks, two focus on supervision and one on the total time carers spent supporting their relatives with dementia.

As mentioned in Section 3.6.1, the questionnaire was designed to separately collect the time the interviewed unpaid carer and other unpaid carers spent on each of the caring

tasks investigated. Unfortunately, however, there was a misunderstanding in how we anticipated the questionnaire would be understood and how the researchers collecting the data interpreted the questionnaire. Section 3.6.4 explains this in further detail. For this reason, I could not distinguish between the time that interviewed unpaid carers spent on the different ADL and IADL tasks and the time contributed by all other unpaid carers. Therefore, the analysis of time spent on ADL and IADL tasks in this analysis reflected the time that *all* unpaid carers provided.

The question on supervision was presented separately from the ADL and IADL question (see Appendix 6.1). This means that for the time carers spent on supervision it was possible to separately analyse time spent by the interviewed carer and time spent by all unpaid carers supporting a person with dementia. Two analyses were provided to reflect this distinction: one model investigated time spent supervising by the interviewed unpaid carer, the other focused on time spent supervising by all unpaid carers. For consistency with the ADL and IADL models, the aggregate model investigating total time spent caring by all unpaid carers only considered the time supervising provided by all unpaid carers. Wimo and colleagues (2002) used a similar approach when investigating factors influencing time carers of people with dementia spent caring in Sweden.

Collecting data on different care tasks bears the risk that time spent supporting the care-recipient could be overestimated as care tasks might overlap. Furthermore, people with dementia often not just need supervision throughout the waking day, but some may also require monitoring at night. In the literature different approaches have been used to address this potential overestimation. Some analyses limit the total time carers could declare spending on all the tasks to 24 hours (Wimo et al., 2002), in others studies adjustments have been made to account for carer sleep (Neubauer et al., 2008; Gustavsson et al., 2011). In my study, the inability to distinguish between the time the interviewed unpaid carer provided and the time all other unpaid carers contributed meant that I was unable to adjust for potential overestimation of time spent caring in a meaningful way.

Furthermore, estimating time spent on care tasks using a recall method bears the risk of introducing bias. For this reason Wimo and colleagues (2010, p.685) tested the RUD instrument in comparison to a diary method and found high agreement for ADL tasks, supervision and total time ‘and lower but acceptable [agreement] for IADL’. In relation to these findings, the issue of co-production of tasks such as housework and shopping falling under the definition of IADLs and the difficulty of distinguishing between time spent on

these tasks for the family (particularly among co-residents) and the additional time spent due to the care needs of the person with dementia has been raised as a potential contributor to the low agreement found (Neubauer et al., 2008, p.1172).

3.6.3 Data analysis

This particular part of my thesis uses cross-sectional data, which was collected as part of the first wave of the MODEM cohort study. Initially, each of the five outcome models outlined above was investigated using multiple regression analysis. Due to the highly skewed distribution of the variables (see Box 3.6.3) several models were explored. First, Generalised Linear Models were explored to accommodate the highly skewed distribution of the outcome variables (Gill, 2001). Generalised linear models are generally expressed as:

$$g(\mu) = \alpha + \beta_1 X_{1i} + \beta_2 X_{2i} + \cdots + \beta_k X_{ki} \quad (1)$$

Here $X_{1i}, \dots, X_{ki}$ represent the observed values of the explanatory variables $X_1, \dots, X_k$ for unit i, and $\alpha, \beta_1, \dots, \beta_k$represent the unknown parameters. The special link function of the model is represented by the $g(\mu)$ of μ. (1) specifies that $g(\mu)$ depends on a set of explanatory variables (Kuha & Lauderdale, 2014/2015, p.137).

In this case, the Modified Park Test was used to identify the appropriate data family (Manning & Mullahy, 2001). Testing for the different distributions suggested that a Poisson distribution would be most appropriate.

The Poisson model commonly is denoted as:

$$f(y|\mu) = \frac{e^{-\mu}\mu^{y}}{y!} = \exp[y\log(\mu) - \mu - \log(y!)]$$

where $y\log(\mu)$ represents the interaction component, identifying $\log(\mu) = \theta$ as the canonical link in (1) and $\mu = b(\theta) = \exp(\theta)$ (Gill, 2001) .

After exploring several models and running post-estimation tests (goodness-of-fit test) it was found that the models did not provide a good fit for the data as heteroscedacity assumptions did not hold and conditional variance exceeded the conditional mean (Cameron & Trivedi, 2014).

The literature suggested that in this case negative binomial regression models should be explored as they include a random component that accommodates the 'uncertainty about the true rates at which events occur for individual cases' (Gardner, Mulvey & Shaw, 1995, p.399; Cameron & Trivedi, 2014). The most commonly used negative binomial regression

model (NB2) is derived from the Poisson-gamma mixture distribution, with mean μ and variance function $\omega_i = \mu_i + \alpha\mu_i^2$(Cameron & Trivedi, 2014, p.74).

The fundamental binomial regression model for an observation *i* is denoted as:

$$\Pr(y|\mathrm{X}_i, d_i) = \frac{\Gamma(y+\theta)}{y!\,\Gamma(\theta)} \frac{\theta^\theta \mu(\mathrm{X}_i, d_i)^y}{(\theta + \mu[\mathrm{X}_i, d_i]^{(\theta+y)}}$$

$$\mathrm{E}(y_i|\mathrm{X}_i, d_i) = \mu(\mathrm{X}_i, d_i)$$

Given the uncertainty around $\tilde{\mu}_i$, the variance of y_i is larger than in a Poisson model:

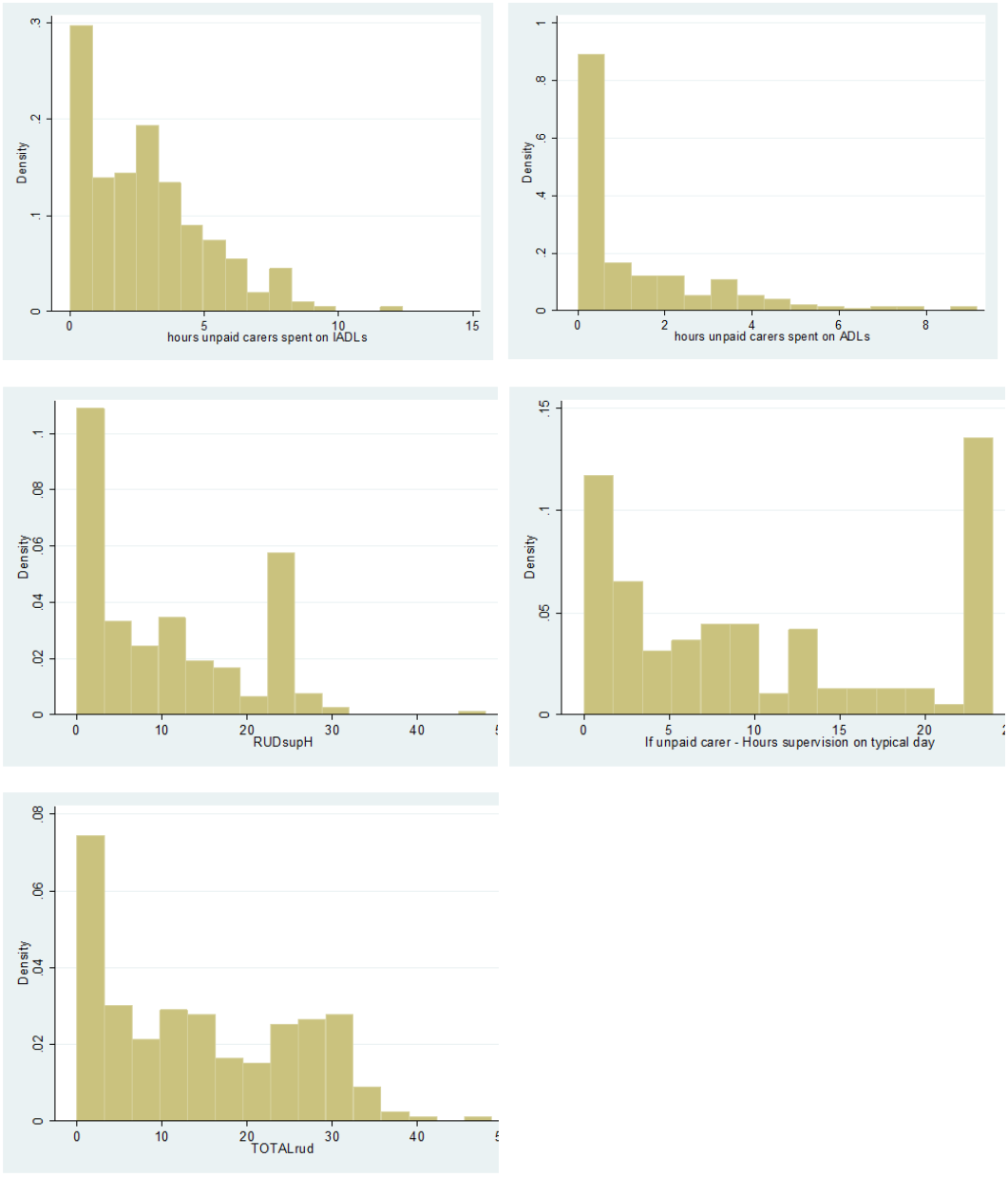
$$\mathrm{Var}(y_i|\mathrm{X}_i, d_i) = \phi(\mu[\mathrm{X}_i, d_i] + \theta^{-1}\mu[\mathrm{X}_i, d_i]^2),$$

Where $\phi = 1$ if the negative binomial model holds and $\phi \neq 1$ if the distribution is over or underdispersed (Gardner, Mulvey & Shaw, 1995, pp.399-400).

Before computing multiple regression models, the five outcome variables were analysed using univariate analyses to investigate potential statistically significant associations ($p<0.05$) between the outcome variables and a number of independent variables hypothesised to be associated with provision of care. Inclusion of variables was driven by aspects in the literature identified as influencing time spent caring as well as carer well-being and quality of life (see Chapter 2). Among variables identified as potential influences on care commitment in the literature were ADL and IADL ability of the care-recipient. Studies have found that care-recipient ADL and IADL abilities predicted care time independently of severity (Gustavsson et al., 2011, p.324). In this study, the Bristol Activity of Daily Living (BADLs) index was used to collect information on care-recipients ADL and IADL needs (Bucks et al., 1996). However, issues with overall model fit were experienced when the variables were introduced to the models.

Next, two models were developed for each of the five outcome variables. The first model, as reported in Chapter 6, focused on investigating variables reflecting solely carer and care-recipient characteristics. This was done to consistently explore and compare the influence of carer and care-recipient characteristics on time spent on ADL, IADL, supervision and total care. The variables investigated included carer age and gender, co-residence, relationship to the care-recipient as well as age and gender of the care-recipient and dementia severity. In these models all predetermined variables set out for analysis were introduced into the model. Only where the model was found not to be significant overall

Box 3.6.3 Distribution of time unpaid carers spent on ADLs, IADLs, supervision and total care



(estimated using the link test (STATA, 2014)) were the different independent variables investigated using a backward selection approach until the variable(s) leading to the violation of the model were identified and removed.

Then a second model was developed for each of the outcome measures. It investigated carer and care-recipient characteristics but also variables for which statistically significant associations had been found in the initial univariate analysis. These models aimed to explore factors influencing time carers spent on ADL, IADL, supervision and total care. As the research question focuses on carer age and gender,

both variables were included in all five models. Similar to the approach taken in Chapter 6, the models were built using a forward selection approach. After the introduction of a new variable, overall model fit and a test to estimate whether the quality of the overall model improved (using the Akaike information criterion) were performed (Akaike, 1974; Wagenmakers & Farrell, 2004). Only where a variable improved the model and the model overall remained significant was the variable added to the model. When the best model was established, post-estimation analysis investigating residuals were performed. The results of the different models explored can be found in Chapter 7. Similar stepwise approaches to investigate RUD data were also used by Wimo and colleagues (2002) and Haro and colleagues (2014).

As it has been recognised in the literature that care commitment between carers looking after a person with dementia in the community and those supporting someone with dementia in institutional care setting differs substantially, only carers of people with dementia living in the community were included in the analysis (Pot, Deeg & Van Dyck, 1997; Borsje et al., 2016; Bleijlevens et al., 2015). This is also consistent with findings from the qualitative study in this thesis (Chapter 5). Furthermore, the focus on carers of people with dementia in the community is consistent with approaches taken in Chapters 4 and 6.

3.6.4 Strengths and limitations of the amended RUD developed for the MODEM project

During the data collection it became clear that the amended questionnaire presented a number of challenges to researchers and respondents. Where possible we addressed small issues during the data collection, but in order not to affect the consistency of the data we abstained from introducing major changes.

First, as pointed out in Section 3.6.1 of this chapter, the graphical design of the questionnaire on our part and some misunderstanding in the communication with the researchers conducting the interviews meant that, for each of the sub-categories of ADLs and IADLs for which we collected information on specific care tasks, carers were asked whether they received support from other unpaid and/or paid carers. The graphical design of the questionnaire suggested that time spent by the paid carer should be collected separately (see Appendix 6.1). Only one column for time spent by unpaid carers, however, meant that the researchers collecting the data interpreted that the time spent by both the interviewed carer and other unpaid carers supporting the person with dementia should be aggregated. We discovered this issue during a conversation approximately halfway through the data collection, but decided to abstain from changes to the data collection in order not to affect data consistency.

Second, researchers collecting the data noted that some people found estimating how much time they spent on the different activities very difficult. It was impossible to verify whether the information provided was accurate. Carers generally experienced less difficulty estimating the time they spend on personal care tasks than on estimating the categories getting around inside and outside or transportation. Furthermore, carers frequently offered their responses as 'twenty minutes every other day'. The researcher then calculated the average time per day. Where respondents experienced difficulties estimating their time spent on specific tasks, the researcher encouraged the interviewees to estimate the time per week or per month.

Third, collecting data on time spent on care tasks, such as shopping, housework or finances, was difficult to estimate for co-resident carers. Particularly spouses often took care of the couple's joint household. This might have resulted in inflated time estimates for people in these situations. Furthermore, difficulties in estimating time spent caring emerged when several unpaid carers were involved in the care provision, as the interviewed carer did not necessarily know how much time other unpaid carers spent on specific tasks. Data collected for this study only represents the information provided by the interviewed carer. Carers of care-recipients interviewed in care homes and day care centres were excluded from this study.

Fourth, when unpaid carers were asked to estimate the time paid carers spent on the specific care tasks, respondents experienced difficulties. Carers were aware of the remit of the paid carer and the overall time that paid carers spent with the care-recipient; however, they might not be aware on how the time was split between different tasks. The researchers suggested that family carers often used the time paid carers covered for themselves. The researchers got the impression that estimating time spent caring by other people included a considerable degree of guesswork. Similar experiences were reported for the item supervision. The ability to estimate supervision time for other carers appeared to be dependent on the cognitive and physical status of the person with dementia. It was easier to estimate supervision for people with advanced dementia than for people with milder forms. One researcher found that when explaining the concept of supervision to carers using the phrase 'supervision is that time you feel you wouldn't be anywhere else doing anything, you do need to be there yet you are not necessarily providing care' very much increased the time carers estimated as supervision. The different researchers collecting the data, however, did not use this explanation consistently.

Fifth, when designing the questionnaire we linked the amended RUD to the Bristol Activities of Daily Living Scale (BADLs) with the objective of using the BADLs as a screening tool to reduce the burden of an already lengthy questionnaire. However, this was not found to be successful. The researchers reported that connecting the two measures did not reduce the interview time. Instead it may have caused some information to be lost. The BADLs collects a lot of detailed information on care-recipients' ability to perform ADL and IADL activities. However, just because someone is able to perform tasks independently does not mean that the person is not receiving support for it. Preparation of food was an example: a lot of interviewees would state that their care-recipient was able to prepare food, but in practice the task had been taken over by a carer. Using the BADLs question on the ability of preparing food meant that we might have lost some information on the provision of support for some of the ADL and IADL tasks. On the other hand, considering a cost perspective, focusing on time spent on tasks the care-recipients were no longer able to perform independently may have given a more realistic picture of care needed. Conversation with the researchers collecting the data suggested that there might be some variability in the data as some researchers have picked up on the implication of using the BADLs as a screening tool; however, it is unclear how consistently this was done.

Chapter 4

Carer characteristics in different datasets

Population-representative datasets contain only limited information on unpaid care and identifiable samples of unpaid carers providing dementia care are very small. This thesis therefore relies on three datasets that specifically have been designed to collect detailed information on people providing care to a relative with dementia in the community in England. As these samples do not have population-representative properties, this chapter compared a number of carer characteristics available in the three studies used in this thesis to the characteristics of people identifying as unpaid carers in the Census 2011 for England and the English Longitudinal Study of Ageing, a population-representative sample of people in England aged 50 and above. This comparison allows for a better understanding of how carers of people with dementia in the datasets used for this thesis compare to unpaid carers in England.

4.1 Comparison of carer characteristics

This chapter compares a number of carer characteristics, outlined in Chapter 2.5 as influential to carer well-being and quality of life, in the three datasets START, SHIELD-CSP-RYCT and MODEM to family carers for people with different needs identified in the population-representative English Longitudinal Study of Ageing (Wave 6) and the Census 2011 for England. As outlined in Chapter 3.3, data used in this thesis comes from the MODEM cohort study conducted in Sussex and the two trial datasets START and SHIELD-CSP-RYCT for which data has been collected in London. While these datasets collected very detailed information on carers of people with dementia, none of the datasets is population-representative. When exploring available datasets, it was found that no population-representative dataset collecting information for England contained detailed information on unpaid carers of people with dementia.

The absence of population-representative information on carers for people with dementia in England made it impossible to explore the representativeness of carers in the START, SHIELD-CSP-RYCT and MODEM samples. However, more is known about people identifying as carers for people with a variety of different needs, some of which may include dementia. Detailed information on a population-representative sample of people providing unpaid care (i.e. not just for people living with dementia) can be found in the English Longitudinal Study of Ageing and the Census 2011 data.

This chapter aims to explore if and how carers of people with dementia (as

represented by carers enrolled in START, SHIELD-CSP-RYCT and MODEM) may differ from carers of people with a variety of needs.

An understanding of similarities and differences is important for the contextual placement of results obtained in the following chapters and to draw comparisons for a wider discussion. Carer characteristics investigated were carer age, gender, ethnic origin, marital status, employment status, educational achievements, relationship to the care-recipient, cohabitation with the care-recipient, housing tenure if carer and carer recipient were cohabiting and self-rated health. For the purpose of comparison, the carer characteristics collected throughout the study-specific questionnaires had to be re-categorised. An overview of how variables were re-categorised to enable comparison can be found in Appendix 4.

In order to enable a comparison between the five datasets it was necessary to introduce an age cut-off for carers of 50 years, as ELSA only collects data on people aged 50 years and above. For the purpose of comparability, carer characteristics in this chapter were illustrated using the two age-bands 50-74 years and 75 years and older. Furthermore, while START, SHIELD-CSP-RYCT and MODEM focus particularly on data related to dementia care provided by family carers in the community, ELSA reflects unpaid care provided by family members to relatives with care needs other than children or grandchildren in any care setting. In this comparison, however, only unpaid carers providing care to recipients aged 65 and over were considered. Differentiations between adult- and under-aged care-recipients or the care setting were impossible to make using aggregate Census data. Census 2011 data included the provision of unpaid care to 'family members, friends, neighbour or others because of long-term physical or mental ill-health or disability, or problems related to old age' (InFuse, 2017).

4.1 Carer gender & age

Consistent with the literature on family carers in general and family carers of people with dementia specifically, a greater proportion of women than men provided care to a relative or friend in all five studies (ONS, 2013a, p.2; Dahlberg, Demack, & Bambra, 2007 p.441). In the dementia-specific databases SHIELD-CSP-RYCT (67.4%), START (68.3%) and MODEM (67%) the proportion of female carers made up about two-thirds of the study population. This was similar in ELSA (64.4%), where care was limited to care-recipients aged 65 and older. In the Census data for England (2011) the distribution between male and female carers was more even (women: 56.2%).

While the overall gender distribution can give some insights into who provides

unpaid care, a clearer picture can be obtained when looking at the proportion of men and women providing care in different age groups. It immediately became clear that the group providing most care were women aged 50 to 74. In MODEM, START and SHIELD-CSP-RYCT between 44.4% (MODEM) and 55.3% (START) of all carers fall into this category. Similar proportions could be found in ELSA (Wave VI) and Census (2011), where 55.3% and 49.0% of carers, respectively, were women aged 50 to 74. More detailed analysis of the 2011 Census showed that the greatest proportional difference between men and women providing care in England could be found in the age group 50 to 64, with women providing 6 percentage points more care than men in the same age group (ONS, 2013a, p.3). The use of broader age bands in this comparison hid this difference.

In ELSA and Census, the second largest group of carers were men aged 50 to 74 (ELSA: 24.8%; Census: 36.0%). Furthermore, both datasets consistently showed that a considerably smaller proportion of carers were men and women aged 75 years and older provided unpaid care. In ELSA, 10.9% of the total carers were men aged 75 and above and 9.10 % were women. In Census this proportion was even smaller, with 7.8% of men and 7.2% of women being in the older age band.

Among family carers of people with dementia, reflected through the datasets SHIELD-CSP-RYCT, START and MODEM, the comparison was not as straightforward. First, the proportion of men aged 50 to 74 providing care in the community was considerably smaller, ranging from 16.2% (MODEM) to 19.4% (SHIELD-CSP-RYCT), than those of carers in ELSA and Census in the same age category. This difference might in part be explained by the exclusion of unpaid carers supporting people with dementia in residential care settings in the dementia-specific datasets, while a differentiation between care at home and in the community cannot be made for ELSA and Census. However, it might also be reflecting the limited involvement of sons in the personal care of their parents identified in the literature (Campbell, 2010; Grigorovich et al., 2016; Ferrant, Pesando & Nowacka, 2014).

Second, the proportion of carers aged 75 and older and supporting a person with dementia was considerably larger than the proportion of carers aged 75 and older in ELSA and Census. In both MODEM (22.6%) and SHIELD-CSP-RYCT (21.2%) the second largest group of carers were women aged 75 and above. Consistently, across the three dementia-specific datasets a greater proportion of older women than men provided dementia care. There were approximately 6% more women than men in this age group in MODEM and SHIELD-CSP-RYCT supporting a person with dementia. In START,

on the other hand, this gender difference was almost negligible, with 13.1% of women and 12.6% of men in this age group providing care.

Differences were also observed when looking at the age distribution within the two age-bands. Carers in START showed the lowest mean age of 55.2 years for both men and women of the younger age band. This was not surprising, as one of the recruitment sites for the trial was a centre for people with early onset dementia. The recruitment process for the trial may have influenced carer mean age as well. Carers in MODEM and SHIELD-CSP-RYCT were on average about 10 years older (mean age 64 years for men and women). While mean age in START and MODEM did not differ for men and women, female carers in SHIELD-CSP-RYCT were slightly younger (62.5 years) than male carers (65.6 years) on average. A similar pattern was also observed for ELSA and Census data. Comparison of mean age of carers in the younger age band showed that carers in ELSA (62.7 years) and Census (60.1) were slightly younger than carers in MODEM (64.9 years) and SHIELD-CSP-RYCT (63.8) and slightly older than carer mean age in START (55.2 years). The older age bands in START and MODEM were rather similar, with mean age of female and male carers being around 80 years. Mean age of carers in SHIELD-CSP-RYCT, ELSA and Census was only slightly younger ranging from 78.4 years (women in Census 2011) to 79.9 years (men in SHIELD-CSP-RYCT). Standard deviations in the older age band were comparably smaller than the standard deviations in the younger age band.

Table 4.1: Overview of characteristics of unpaid carers and their care-recipients in SHIELD-CSP-RYCT, START and MODEM, categorized by gender and age group (50-75; ≥75)

	SHIELD-CSP-RYCT (baseline)				START (baseline)				MODEM (wave I)			
	Age <75, mean ±SD		Age≥75, mean ±SD		Age <75, mean ±SD		Age ≥75, mean ±SD		Age <75, mean ±SD		Age ≥75, mean ±SD	
Variables	Men (n=46)	Women (n=105)	Men (n=35)	Women (n=50)	Men (n=38)	Women (n=110)	Men (n=25)	Women (n=26)	Men (n=48)	Women (n=132)	Men (n=50)	Women (n=67)
Age Carer												
	65.63 (6.43)	62. (7.04)	79.91 (3.68)	78.92 (3.17)	55.23 (10.36)	55.23 (11.56)	80.28 (3.99)	79.68 (3.73)	64.6 (7.13)	64.11 (6.96)	80.56 (4.38)	80.21 (3.35)
	Age <75, (%)		Age≥75, (%)		Age <75, (%)		Age ≥75, (%)		Age <75, (%)		Age ≥75, (%)	
Ethnic origin												
White	43 (93.48%)	98 (93.33%)	32 (91.43%)	50 (100%)	31 (86.11%)	97 (92.38%)	22 (91.67%)	22 (88.00%)	48 (100%)	130 (99.24%)	49 (100%)	67 (100%)
Black	3 (6.52%)	4 (3.81%)	0 (0.00%)	0 (0.00%)	3 (8.33%)	6 (5.71%)	2 (8.33%)	3 (12.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
Asian	0 (0.00%)	3 (2.86%)	2 (5.71%)	0 (0.00%)	2 (5.56%)	2 (1.90%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
Other	0 (0.00%)	0 (0.00%)	1 (2.86%)	0 (0.00%)	0 (0.00%)	0	0	0	0 (0.00%)	1 (0.76%)	0 (0.00%)	0 (0.00%)
Relationship status of the carer												
Without partner	8 (17.39%)	16 (15.09%)	0 (0.00%)	2 (4.00%)	16(42.11%)	32(29.09%)	3 (12.5%)	2 (07.69%)	21 (43.75%)	59 (44.70%)	1 (2.00%)	1 (1.49%)
Coupled	38 (82.61%)	89 (84.76%)	35 (100%)	48 (96.00%)	22 (57.89%)	78 (70.91%)	21 (87.50%)	24 (92.31%)	27 (56.25%)	73 (55.30%)	479 (98.00%)	66 (98.51%)
Employment status												
Employed	9 (19.57%)	28 (26.65%)			17 (44.74%)	50 (45.45%)			8 (24.24%)	19 (20.21%)		
Not working	37 (80.43%)	77 (73.33%)	35 (100%)	50 (100%)	21 (55.26%)	60 (54.55%)	23 (92.00%)	23 (88.46%)	25 (75.76%)	75 (79.79%)	31 (100%)	25 (100%)
Education												
No qualifications	27 (58.70%)	64 (60.95%)	25 (71.43%)	40 (80.00%)	8 (21.05%)	24 (21.82%)	9 (36.00%)	12 (46.15%)	4 (8.33%)	16 (12.12 %)	18 (36.00%)	20 (29.85%)
Further education	12 (26.09%)	27 (25.71%)	7 (14.00%	7 (14.00%)	14 (36.84%)	37 (33.64%)	3 (12.00%)	3 (11.54%)	15 (31.25%)	55 (41.67%)	12 (24.00%)	19 (28.36%)
Higher education	7 (15.22%)	14 (13.33%)	3 (8.57%)	3 (6.00%)	11 (28.95%)	32 (29.09%)	7 (28.00%)	6 (23.08%)	22 (45.83%)	39 (29.55%)	12 (24.00%)	12 (17.91%)
Foreign/ Other	-	-	-	-	*5 (13.16%)*	*17 (15.45%)*	*6 (24.00%)*	*5 (19.23%)*	*7 (14.58%)*	*22 (16.67%)*	8 (16.00%)	16 (23.88%)

	SHIELD-CSP-RYCT (baseline)				START (baseline)				MODEM (wave I)			
	Age <75, (%)		Age≥75, (%)		Age <75, (%)		Age ≥75, (%)		Age <75, (%)		Age ≥75, (%)	
Variables	Men (n=46)	Women (n=105)	Men (n=35)	Women (n=50)	Men (n=38)	Women (n=110)	Men (n=25)	Women (n=26)	Men (n=48)	Women (n=132)	Men (n=50)	Women (n=67)
Relationship to person with dementia												
Spouse or partner	26 (56.52%)	57 (54.29%)	35 (100%)	48 (96.00%)	16 (42.11%)	41 (37.27%)	25 (100.00%)	24 (92.31%)	*24 (50.00%)*	*63 (47.73%)*	49 (98.00%)	66 (98.51%)
Child	16 (34.78%)	45 (42.86%)	0 (0.00%)	0 (0.00%)	18 (47.37%)	59 (53.64%)	0	1 (3.85%)	*22 (45.83%)*	*58 (43.94%)*	0 (0.00%)	0 (0.00%)
Other family	1 (2.17%)	3 (2.86%)	0 (0.00%)	0 (0.00%)	1 (7.89%)	6 (5.45%)	0	1 (3.85%)	*1 (2.08%)*	*6 (4.55%)*	1 (2.00%)	1 (1.49%)
Other relationship (unpaid)	3 (6.52%)	0 (0.00%)	0 (0.00%)	2 (4.00%)	3 (7.89%)	4 (3.64%)	0	0	*1 (2.08%)*	*5 (3.79%)*	0 (0.00%)	0 (0.00%)
Cohabitation with care-recipient												
Yes	34 (73.91%)	73 (69.52%)	35 (100%)	50 (100%)	24 (63.16%)	62 (56.36%)	23 (92.00%)	23 (88.46%)	*27 (56.25%)*	*71 (53.79%)*	46 (92.0%)	57 (85.07%)
No	12 (26.09%)	32 (30.48%)	0 (0.00%)	0 (0.00%)	14 (36.84%)	48 (43.64%)	2 (8.00%)	3 (11.54%)	*21 (43.75%)*	*61 (46.21%)*	4 (8.00%)	10 (14.93%)
Housing tenure for co-resident carers												
Owner-occupied	28 (82.35%)	63 (86.30%)	31 (88.57%)	44 (88.00%)	19 (79.17%)	40 (65.57%)	21 (91.30%)	11 (50.00%)	*23 (85.19%)*	*59 (88.06%)*	*39 (92.86%)*	*51 (92.73%)*
Other rental agreements	6 (17.65%)	10 (13.70%)	4 (11.43%)	6 (12.00%)	5 (20.83%)	21 (34.43%)	2 (8.70%)	11 (50.00%)	*4 (14.81%)*	*8 (11.94%)*	*3 (7.14%)*	*7.27%)*
Missing	*0*	*0*	*0*	*0*	*0*	*1*	*0*	*1*	*21*	*65*	*4*	*2*
Self-rated health												
Very poor to fair	12 (26.09%)	42 (40.00%)	15 (42.86%)	25 (51.02%)	4 (10.81%)	27 (24.77%)	9 (36.00%)	12 (46.15%)	*6 (12.50%)*	*15 (11.36%)*	5 (10.00%)	20 (30.77%)
Good to excellent	34 (73.91%)	63 (60.00%)	20 (57.14%)	24 (48.98%)	33 (89.19%)	82 (75.23%)	16 (64.00%)	14 (53.85%)	*42 (87.50%)*	*117 (88.64%)*	45 (90.00%	45 (69.23%)
	0	0	0	1	*1*	*1*	*0*	*0*	*0*	*0*	*0*	*2*

Table 4.2: Overview of characteristics of unpaid carers and their care-recipients in Census 2011 (England) and ELSA Wave VI, categorized by gender and age group (50-75; ≥75)

	ELSA (Wave VI)				Census 2011 (England)			
	Age <75, mean ±SD		Age≥75, mean ±SD		Age <75, mean ±SD		Age ≥75, mean ±SD	
Variables	Men (n=196)	Women (n=437)	Men (n=86)	Women (n=72)	Men (n=56,191)	Women (n=76,475)	Men (n=12,197)	Women (n=11,203)
Age Carer								
	63.52 (5.89)	61.9 (6. 27)	79.57(3.86)	79.81 (4.47)	60.32 (6.33)	59.78 (6.26)	78.98 (4.38)	78.39 (4.11)
	Age <75, (%)		Age≥75, (%)		Age <75, (%)		Age ≥75, (%)	
Ethnic origin								
White	173 (98.86%)	359 (95.99%)	83 (98.81%)	70 (98.59%)	52,986 (94.30%)	72,230 (94.45%)	11,755 (96.38%)	10,831 (96.68%)
Black		6 (1.60%)	1 (1.19%)	0	711 (1.27%)	1,190 (1.56%)	140 (1.15%)	127 (1.13%)
Asian	2 (1.14%)	7 (1.87%)		0	2,173 (3.87%)	2,659 (3.48%)	261 (2.14%)	218 (1.95%)
Other		2 (0.53%)		1 (1.41%)	321 (0.57%)	396 (0.52%)	41 (0.34%)	27 (0.24%)
Missing	*21*	*63*	*2*	*1*	*0*	*0*	*0*	*0*
Relationship status of the carer								
Without partner	15 (8.33%)	82 (19.66%)	1 (1.19%)	11 (15.28%)	12,797 (22.77%)	21,107 (27.40%)	1349 (11.06%)	2,910 (25.98%)
Coupled	165 (91.67%)	335 (80.34%)	83 (98.81%)	61 (84.72%)	43,394 (77.23%)	55,368 (73,40%)	10,848 (88.94%)	8,293 (74.02%)
		20						
Employment status								
Employed	76 (38.78%)	156 (35.79%)	1 (1.16%)	2 (2.78%)	30,569 (54.59%)	36,066 (47.32%)	513 (4.21%)	369 (3.3%)
Not working	120 (61.22%)	281 (64.39%)	85 (98.84%)	70 (97.22%)	25,433 (45.41%)	40,149 (52.68%)	11,662 (95.79%)	10,804 (76.70%)
Missing			*0*	*0*	*189*	*260*	*22*	*30*
Education								
No qualifications	37(19,17%)	100 (23.04%)	28 (33.73%)	25 (34.72%)	12,534 (22.31%)	20,844 (27.26%)	5,669 (46.48%)	6,412 (57.23%)
Further education	99 (51.30%)	222 (51.15%)	36 (43.37%)	32 (44.44%)	22,635 (40.28%)	30,307 (39.63%)	3,088 (25.32%)	2,090 (18.66%)
Higher education	39 (20.21%)	60 (13.82%)	12 (14.46%)	4 (5.56%)	17,599 (31.32%)	21,173 (27.69%)	2,598 (21.30%)	1,931 (17.24%)
Foreign/ Other	18 (9,33%)	52 (11.98%)	7 (8.43%)	11 (15.28%)	3,423 (6.09%)	4,151 (5.43%)	842 (6.90%)	770 (6.87%)
Missing	*3*	*3*	*3*	*0*	*0*	*0*	*0*	*0*

	ELSA (Wave VI)				Census 2011 (England)			
	Age <75, (%)		Age≥75, (%)		Age <75, (%)		Age ≥75, (%)	
Variables	Men (n=196)	Women (n=437)	Men (n=86)	Women (n=72)	Men (n=56,191)	Women (n=76,475)	Men (n=12,197)	Women (n=11,203)
Relationship to care-recipient								
Spouse or partner	61 (31.12%)	106 (24.26%)	71 (82.56 %)	53 (73.61%)				
Parent/ - in-law	97 (49.49%)	214 (48.97%)	1 (1.16 %)					
Other family	16 (18.16%)	31 (7.09%)	3 (3.49 %)	6 (8.33%)				
Other relationship (unpaid)	22 (11.22%)	86 (19.68%)	11 (12.79%)	13 (18.06%)				
Cohabitation								
Yes	85 (43.37%)	167 (38.22%)	73 (94.88 %)	56 (77.78%)				
No	111 (56.63%)	270 (61.78%)	13 (15.12 %)	16 (22-22%)				
Housing tenure for co-resident carers								
Owner-occupied	68 (80.00%)	134 (81.21%)	60 (82.19%)	53 (94.64%)	49,192 (82.99%)	63,136 (83.28%)	9,909 (83.28%)	9,007 (82.55%)
Other rental agreements	17 (20.00%)	31 (18.79%)	13 (17.81%)	3 (5.36%)	9,465 (17.01%)	12,679 (16.72%)	2,054 (17.17%)	10,904 (17.45%)
Missing	0	2	0	0	534	660	234	292
Self-rated health								
Very poor to fair	31 (16.76%)	74 (17.49%)	23 (31.51%)	17 (26.15%)	17,915 (31.88%)	22,909 (29.96%)	7,254 (59.47%)	6,860 (61.23%)
Good to excellent	154 (83.24%)	349 (82.51%)	50 (68.49%)	48 (74.85%)	38,276 (68.12%)	53,566 (70.04%)	4,943 (40.53%)	4,343 (38.77%)
Missing	11	14	13	7				

Ethnic origin

For the purpose of this comparison the variable ethnic origin was arranged into the four groups: ‘White’, ‘Black’, ‘Asian’ and ‘Other’. All datasets offered more categories, but literature on caring at middle and older age in the United Kingdom suggests that the ethnic diversity of carers might be limited (ONS, 2013b). The comparison of carer’s ethnicity showed that in all five studies, with over 85% of the study population, the largest group declared itself to be ‘White’. The very low numbers of Black and Minority Ethnic (BME) groups among carers of all age and gender groups is consistent with the literature, indicating that migration patterns created a situation where minority groups have not yet reached middle and late life in numbers that would appear significant in this comparison (Gov.UK, 2018; Houses of Parliament, 2018). There is, however, a BME population that experiences the provision of care for frail elderly people. In order to get a better understanding of these groups a specific study design oversampling these population groups, as done in Understanding Society, would be necessary, but cannot be covered in this study (Understanding Society, 2018). For this reason, ethnic origin will not be considered in the analysis of SHIELD-CSP-RYCT, START and MODEM data in the following chapters.

Relationship status of the carer

The next variable investigated was relationship status of the carer. This variable was derived from the variable marital status, but, has been coded slightly differently to reflect whether people identify as ‘coupled’ or living ‘without partner’. The category ‘coupled’ includes people who stated to be married, in a civil partnership or cohabiting with a partner, the category ‘without partner’ consists of people who stated to be ‘single’, ‘separated’, ‘divorced’ or ‘widowed’. This distinction was preferred as it is hypothesised that the presence or absence of a partner, rather than people’s legal marital status, might influence care patterns. There is, for example, evidence that sons providing hands-on care are more likely to be without a partner; while among older carers the largest proportion of unpaid care is provided to people’s partners (Campbell, 2010; ONS, 2013a; Vlachantoni, 2010).

The majority of carers of both age and gender groups in the studies considered in this comparison were married, in a civil partnership or cohabiting with a partner. In both ELSA (Wave VI) and Census 2011 (England) data, the vast majority of male and female carers aged 50 to 74 years (over 73%) fell into this category. Comparing the relationship status of men and women in this age group showed that over 90% of men lived in partnership, while this was only the case for 80% of women.

Greater variation was found in the dementia-specific datasets. In SHIELD-CSP-RYCT, over 80% of male and female carers in the younger age group lived in a partnership. In START, 57.9% of men and 70.9% of female carers fell into the partnered category. Among carers enrolled in MODEM fewer than 60% (male 56.3%; female: 55.3%) were married, in a civil partnership or cohabiting. The proportion of carers in START and MODEM that declared that they did not to live in a partnership amounted to over 40% of men. The proportion of un-partnered women in the younger age group was also much higher in MODEM than in the other datasets.

Among carers aged 75 years and over the pattern showed greater similarity. The majority of male and female carers in this group were married (over 87% in START, SHIELD-CSP-RYCT and MODEM). The same was true for male carers in ELSA (93.3%) and Census 2011 (88.9%). Fewer women of this age group, however, were married (ELSA: 84.7%; Census: 74.0%). These findings are consistent with demographic trends showing that women continue to live longer than men. The difference could therefore be due to a larger number of widowed wives (ONS, 2017b).

Employment

Another interesting feature when comparing the dementia-specific datasets to data on carers in the general population was the distribution of employment. In ELSA (Wave VI), only 36.8% of female and 37.8% of male carers younger than 75 were in employment. This amounted to 47.3% female and 54.6% male carers of the sample in the Census 2011 data. The difference observed might be linked to a difference in mean age between Census and ELSA data. Carers in Census on average were a little younger than carers in ELSA, which might have affected the proportion of carers in employment, particularly in an age band that includes the age at which most people enter retirement. In addition, carers in ELSA only cared for people aged 65 and older, while a proportion of carers in Census provided care for children. Carrying responsibility for dependents could be an incentive to stay in employment for longer.

Differences could also be observed between the dementia-specific datasets. While approximately 45% of male and female carers in START were in employment, this was only the case for 21.6% of carers in MODEM and between 20% of men and 27% of women in SHIELD-CSP-RYCT. The larger numbers of carers in employment in START might in part be explained by the recruitment strategy, which specifically targeted a centre for people with early onset dementia and might therefore also be linked to the comparatively younger age of carers in this age band.

A slightly larger proportion of men were classified as working in ELSA (Wave

VI), Census 2011 (England) and MODEM, while in SHIELD-CSP-RYCT and START slightly more women than men were in the labour force. The Office for National Statistics found that overall women provided more unpaid care than men, irrespective of working full-time, part-time or being unemployed. On the other hand, while the number of men identifying as 'looking after the home' was very small in comparison to women, nearly half of those men also provided unpaid care while this was the case for only a quarter of women (ONS, 2013a, p.15-18).

Education

Linked to employment is the level of education achieved by carers. The categorisation of educational qualifications was found to vary considerably between the different datasets. For the purpose of comparability, different achievements of education were grouped into four categories: 'no qualification', 'further education', 'higher education' and 'foreign/other'. The category 'further education' includes secondary education (GCSE) and corresponding national vocational qualifications, while 'higher education' includes university qualifications and higher professional qualifications. A cut-off between no qualification and a rather broad category for further education was chosen due to the overlap between the variables collected. A detailed breakdown of the different categories for each of the datasets can be found in Appendix 4.

There was considerable variation in educational qualifications between datasets. In Census (about 40%) and ELSA (around 50%) the largest group of men and women aged 50 to 74 had obtained qualifications in further education, which include GCSE, O-Level or NVQ qualifications. Among male carers, a considerable proportion in both datasets also had qualifications at degree level (ELSA: 20%, Census 31%). The second largest group of women in ELSA (23%) declared not to have obtained a qualification, while in Census approximately equal proportions of women declared to have no educational qualifications or qualifications at degree level (27%). Further variation can be found in the three datasets used in this thesis.

In START, similarly to ELSA and Census, 37% of men and 34% of women had completed further education. There was little variation between genders in terms of educational qualifications in START. In MODEM, on the other hand, more than 45% of men had achieved degree-level education. Among the women, the largest group (42%) had vocational qualifications, but almost 30% had also achieved degree-level qualifications. The picture was different in SHIELD-CSP-RYCT, where the majority of both men and women in the younger aged band (approximately 60%) said they had no formal educational qualifications.

Consistent with demographics, most commonly carers in the age-band 75 and above did not have formal qualification across datasets. The only exception was found among male carers in ELSA (Wave VI), where slightly more men had obtained a qualification in further education compared to those without any qualifications. SHIELD-CSP-RYCT, as in the younger age band, showed the most distinct pattern among carers aged 75 and above. Over 70% of men and 80% of women in the dataset declared not having educational qualifications. In contrast, in the same age group, over 20% of men and women in START and over 20% of men in MODEM had qualifications at degree level. This is considerably higher than carers in ELSA, where only 15% of men and 5% of women had qualifications at degree level. Carers in Census were more comparable to START and MODEM, with 21% of men and 17% of women aged 75 and older having achieved the highest level of educational qualifications.

Relationship to care-recipient

The relationship to the care-recipient was categorised differently in the five datasets. For the purpose of comparability, relationship was coded into the four categories, 'spouse or partner', 'filial carer', 'relative' and 'other'. Filial carers were classified as people caring for a parent or parent-in-law. The category 'relative' included any other family relationships captured in the datasets, while the category 'other' covered friends and other relationships (for details see Appendix 4). In ELSA and Census the data was collected based on the care-recipient, which means that when classifying adult child carers it was appropriate to use the categories 'parent' (ELSA) and 'mother or father' (Census).

In MODEM and SHIELD-CSP-RYCT, most carers aged 50 to 74 years supported their spouse or partner, while in START the largest carer group cared for a parent or parent-in-law. In START, approximately 50% of carers looked after a parent or parent-in-law. However, particularly in MODEM, the difference between men and women supporting a spouse (nearly 50%) and those looking after parent with dementia (approximately 44%) was small. The traditional gender pattern, where men are more likely to provide care to spouses than to parents, did not hold true for the 50 to 74 year olds in START and in ELSA. In both datasets, the largest proportion of men (47.4% in START and 49.5% in ELSA) provided filial care (ONS, 2013a).

Among carers 75 years and older, more than 92% provided care to their spouse or partner in the three dementia-specific datasets. Similarly in ELSA, the largest group cared for a partner or spouse, but over 12% of men and over 18% of women stated that they were looking after people outside the immediate family.

Cohabitation

As people care for their frail relatives, significant numbers of people reported living with their care-recipient. While this might be expected for elderly carers looking after their spouses (more than 85%), this was also the case in the younger age band. Over half of carers aged 50 and 74 in START, MODEM and SHIELD-CSP-RYCT lived with the person with dementia they cared for. Reported numbers in ELSA (Wave 6) were slightly smaller. In this dataset, approximately 43% of male carers and 38% of female carers younger than 75 lived with the person they care for. Among people aged 75 and above living with the person the pattern in ELSA (WAVE 6) was comparable to findings from the three dementia-specific datasets. Approximately 95% of men and 78% of women providing unpaid care in this age group were cohabitating with their care-recipient across datasets.

Housing tenure for co-resident carers

Another important socio-demographic variable in England is housing tenure. For this comparison housing tenure was dichotomized into 'owner-occupied' and 'rental-agreement', whereby rental agreements covered a variety of agreements, such as rented from councils, housing associations or a private person (overview in Appendix 4). For carers in MODEM, START and SHIELD-CSP-RYCT, housing tenure was based on their co-resident care-recipient. In ELSA (Wave VI) housing tenure was based on the carer's housing tenure. For the purpose of comparability only co-resident carers were identified in ELSA Wave VI. With the available Census 2011 data, it was not possible to make a distinction between whether or not the carer resided with the care-recipient. Housing tenure in Census 2011 was based on the carer. The proportion of owner-occupied housing was high (over 80%) for men and women in both age groups in four of the datasets compared. Only in START was the proportion of ownership considerably smaller among female carers in both age bands. Only about 65% of women the younger age band and 50% of women in the older age band declared to live in owner occupied houses.

Self-rated health

The literature on family carers reports widely on negative health outcomes due to caring (Gusi et al., 2009; von Känel et al., 2008). While no such assumptions can be drawn from comparing these cross-sectional databases, self-rated health will be used in the analysis of other chapters of this thesis. The response options for carers' self-rated

health varied slightly between datasets. For this reason, the variable self-rated health was dichotomized into ‘very poor to fair’ and ‘good to excellent’ (see Appendix 4).

The majority of carers in all datasets declared their health to be ‘good to excellent’. It is, however, noteworthy that in SHIELD-CSP-RYCT, 26% of men and 40% of women in the younger age group declared their health as ‘very poor to fair’. The proportion of carers in ‘very poor to fair’ health in the other four datasets was smaller (START: 21.2%, MODEM: 11.7%, ELSA: 25.4% and Census: 30.8%). A greater proportion of women than men declared their health to be ‘very poor to fair’ in the datasets SHIELD-CSP-RYCT, START and ELSA, while in MODEM and Census 2011 proportionately more men younger than 75 declared to be in poor health.

Among carers aged 75 and above, the pattern shifted: increasing numbers of people declared their health as very poor to fair, but there was substantial variation between the datasets. The largest proportion of carers that indicated poor health was found in the Census 2011 (England) database where 59.5% and 61.2% of male and female carers, respectively, declared themselves to be in poor health. In ELSA (Wave VI) this was only the case for about 30% of older carers. In the three dementia-specific studies the majority of carers of the older age group declared their health to be good to excellent.

4.2 Discussion

The carer characteristics explored above provided an idea about similarities and differences of carers in the general datasets ELSA (Wave VI) and Census 2011 (England) and the dementia-specific databases START, SHIELD-CSP-RYCT and MODEM. All five datasets shared the finding that overall more women than men provide unpaid care. This pattern is supported across the literature (ONS, 2013a; ONS, 2016a; Carmichael, 2011; Ferrant, Pesando & Nowacka, 2014).

As outlined above, in Census no distinction could be made with regards to the age of the care-recipient. Within ELSA data, however, it was possible to restrict care provision to people aged 65 and over. This made the comparison between carers in ELSA and those in START, SHIELD-CSP-RYCT and MODEM more meaningful, as the majority of people living with dementia are aged 65 and older (Prince et al., 2014; Alzheimer’s Association, 2013). The overall comparison of carers showed similar age and gender distributions. However, in ELSA proportionately more men aged 50 to 74 were found to provide care than in the dementia-specific datasets. This might have been due to the fact that in ELSA care provision was not limited to care in the community. In START, SHIELD-CSP-RYCT and MODEM, in contrast, only unpaid carers supporting

people with dementia in the community were considered. Evidence from the literature suggests that particularly male filial carers, who are likely to fall into the younger age group, avoid the provision of personal care and more often take on managerial tasks (Campbell, 2010; Grigorovich et al., 2016; Ferrant, Pesando & Nowacka, 2014). People with dementia, due to the progression of cognitive impairment, may develop complex care needs faster than people living with other conditions. Where managerial support may no longer be sufficient, sons might be more likely to arrange for the provision of institutional care than spouses or daughter (López et al., 2012). The hypothesis that particularly sons provide predominantly managerial support is in part supported by data from the Office of National Statistics. It shows that the proportion of men providing more than 20 hours of care in age group 50 to 64 years is considerably lower than that of women (ONS, 2013a; ONS, 2016a).

However, in the age group 65 and older, this picture shifts and ELSA, Census and START data shows that roughly equal proportions of men and women provided this type of care. The change in pattern is particularly driven by an increasing number of men supporting their wives with care needs (Arber & Ginn, 1995; Glaser & Grundy, 2002; Del Bono, Sala & Hanckock, 2009; Vlachantoni, 2010; ONS, 2013a). Increasing male life expectancy might enable more couples to grow old together, and this might be an underlying factor in this observation (Public Health England, 2017b; Bennett et al., 2015). In addition, even though women continue to have longer life expectancy than men, women are also more likely to spend more years in ill-health (Kingston et al., 2017; Public Health England, 2017b). Evidence from the literature confirms that among the oldest old, there are more men than women providing care (ONS, 2013a; Vlachantoni, 2010; Dahlberg, Demack & Bambra, 2007). In both SHIELD-CSP-RYCT and MODEM, on the other hand, the gender difference in care provision did not disappear in the older age group. Approximately six percentage points more women than men aged 75 and above are providing care in the community. The underlying reason for this observation is not clear; however, it might be possible that women were more likely to self-identify as carers than men.

Differences between carers in Census and ELSA and carers of people with dementia could be observed with respect to the proportion of older carers in the datasets. The proportion of older people providing unpaid care in both Census and ELSA was comparably smaller than in the datasets focusing on carers of people with dementia. This is consistent with findings from Bartfay and Bartfay (2013), who also found carers of people with dementia to be comparably older than those caring for

people with other illnesses. The increasing prevalence of dementia with age and the growing number of couples who due to increasing longevity are able to grow old together might be two factors that influence a situation, in which more spouses become carers of their partners at very old age (Prince et al., 2014; Alzheimer's Association, 2013; Public Health England, 2017b; Bennett et al., 2015; Carmichael & Ercolani, 2014).

Another variable for comparison was whether or not carers lived in partnership. Across the datasets, the majority of unpaid carers were married or lived with their partner, and this was particularly true among carers aged 75 and older. These findings are consistent with the discussion above showing that men predominantly provide care for their spouses.

A comparably larger proportion of carers who were single, separated, divorced or widowed could be found in the age group 50 to 74 among men in both START and MODEM and for women in MODEM. Comparing this pattern to the relationship of the care dyads showed that there were slightly more male filial carers in START and MODEM. This pattern reflects observations from the literature, where sons engaging in the provision of personal care in the community were predominantly single (Arber & Ginn, 1995; Campbell, 2010; Friedemann & Buckwalter, 2014). Relationship status does not seem to affect provision of care among daughters (Arber & Ginn, 1995; Vlachantoni, 2010; ONS, 2013a). Overall, however, the proportion of filial and spouse carers were comparable between ELSA, MODEM, START and SHIELD-CSP-RYCT.

Another variable linked to carers' relationship status is cohabitation of the care dyad. As can be seen consistently in the older age band, spouse carers tend to live with their care-recipient (Wanless et al., 2006; Hirst, 2002; Vlachantoni, 2010; Carmichael & Ercolani, 2014). It could also be observed that across datasets more men than women lived with the person they cared for. This might mean that when sons acted as the main carer, they were more likely than daughters to live with the parent they support (Campbell, 2010; Arber & Ginn, 1995). This is consistent with literature reporting that women throughout their lives are more likely than men to provide extra-residential care (Arber & Ginn, 1995).

The five datasets were also consistent in that among cohabiting care dyads, the majority were house owners. Overall, slightly fewer female than male carers reported being owner-occupiers. While it is impossible to draw conclusions from this observation, it might be an indicator of women providing care being socioeconomically more vulnerable. In the literature, women were found to bear greater economic costs

from the provision of unpaid care, as many women are unable to maintain employment or find themselves only able to work part-time due to the care demands placed on them (McGuiness, 2018). The limited pension contribution provided by women in these situations can have implications for their socioeconomic security into old age (Carmichael, 2011; Vlachantoni, 2010; McGuiness, 2018; Bennett & Daly, 2014).

In this comparison, employment status, however, showed some variation. It was found that proportionately more male than female carers were in employment in Census, ELSA and MODEM than in SHIELD-CSP-RYCT and START where no considerable gender differences could be observed. The greater difference between male and female employment in Census might have been due to the inclusion of childcare in the data. Furthermore, while employment rates in START were similar to rates in Census and ELSA, these were considerably lower in MODEM and SHIELD-CSP-RYCT. The greater proportion of employed carers in START may have been due to the inclusion of a centre for people with early onset dementia for recruitment. This may have meant that the partner had to continue working in order to support the family. Therefore, this observation might be linked to the slightly higher mean age of carers in both MODEM and SHIELD-CSP-RYCT.

Comparison of educational qualifications showed that carers of people with dementia in the younger age band were slightly less educated than carers in Census and ELSA. However, there was considerable variation between the dementia-specific datasets. Carers in START and MODEM reported higher educational achievements than carers in SHIELD-CSP-RYCT. Perhaps the provision of unpaid care in the age band 50 to 74, which included a substantial proportion of filial carers, might in part be associated with the opportunity costs among potential unpaid carers available. It is known that children with lower income tend to live in closer proximity to their parents and are more likely to provide care than children with higher incomes (Alzheimer's Association, 2013). In the absence of information on carer income, educational achievements could act as a proxy. However, particularly men in the age band 50 to 74 and women aged 75 and older who participated in MODEM were comparably more educated than their counterparts in START and SHIELD-CSP-RYCT. This suggests that difference in educational patterns could also be due to socio-economic differences in the areas where the data was collected.

Another variable compared was self-rated health. Overall, carers across datasets rated their health highly. Furthermore, consistent with the literature, a greater proportion of men across datasets rated their health as 'good and very good' compared to women.

The literature is not clear on gendered patterns with respect to carers' physical health. Some studies suggest that they are more likely to experience worse health, while others did not establish gender differences (Gibbons et al., 2014; Argimon et al., 2004; Aravena, Albala & Gitlin, 2018; Arango Lasprilla et al., 2009; Bell, Araki & Neumann, 2001). Consistency between the five datasets compared, however, was found with respect to self-rated health in the older age band. The proportion of carers rating their health highly diminished in the older age band. This is consistent with findings showing that the risk of living with disability increases with old age (Grundy, Tomassini & Festy, 2006; Kingston et al., 2017)

Finally, the comparison of carer ethnicity reflected a pattern also observed in general population statistics. The majority of people in England aged 60 and older identifies as 'white'. This pattern is primarily driven by the ageing post-war 'baby boom' generation (Gov.UK, 2018; Houses of Parliament, 2018). This distribution does not mean that the care patterns and resulting needs of people identifying with other ethnic groups should not receive attention. However, it highlights that in order to compare carers of different ethnic groups, more attention needs to be paid to sampling.

Overall, this descriptive comparison of characteristics of unpaid carers in the general population with selected samples of unpaid carers of people with dementia showed no substantial differences. Particularly, unpaid carers in ELSA who looked after people aged 65 and over were found to be similar to carers of people with dementia. Slightly greater variation was found between carers in the dementia-specific datasets START, SHIELD-CSP-RYCT and MODEM and carers identified from the Census 2011. These differences might have been due to the inability to distinguish between unpaid care provided to children, adults and older people in the aggregate Census data. Overall, carer characteristics in the datasets MODEM, START and SHIELD-CSP-RYCT, on which the analysis in this thesis will be build, appear to sit well with characteristics of unpaid carers aged 50 and above identified from the population-representative samples of ELSA (Wave VI) and Census (2011).

4.2.1 Limitations

Following the comparison of carer characteristics it is important to highlight some limitations regarding the comparability and interpretation of the data.

First, as pointed out above, it was impossible to obtain information regarding the gender, age or care needs of care-recipients in ELSA (WAVE VI) and Census 2011 (England), which limits the comparability to the dementia-specific datasets.

Second, the different categories used to collect information on education in the five datasets made the categorisation problematic. In particular, the dataset SHIELD-CSP-RYCT - which collected the categories ‘school leaver 14-16’ and ‘school leaver age 18’ - caused difficulties. It was decided that ‘school leavers aged 14 to 16’ are less likely to have achieved an educational qualification than school leavers at 18 and the former have therefore been grouped into the category ‘no qualification’ while school leavers aged 18 were classified as ‘further education’.

Finally, the variable housing tenure also led to difficulties. First, in the dementia-specific datasets only housing tenure of the care-recipient was collected. Therefore, housing tenure could only be established for carers who were co-resident. It is, however, unclear whether the owner in the category owner-occupied housing is the care-recipient or the carer. This may be more problematic for adult children co-residing with their parents than for spouses or partners who are more likely to jointly own the property with the care-recipients. Furthermore, in ELSA housing tenure is defined based on the carer but for the purpose of comparison housing tenure has been limited to co-resident carers. In Census this adaption was impossible leading to an overview of housing tenure of all carers identified in the dataset.

Chapter 5

Are there differences in how husbands, wives, daughters and sons of people with dementia experience the provision of care and how they construct well-being?

Conceptualising carer well-being, as outlined in Chapter 2 is complex. Numerous indicators, some of which are explored in Chapters 2 and 6, are frequently used to quantitatively measure carer well-being.

In this chapter qualitative interviews with seven husbands, seven wives, six daughters and five sons looking after their spouses and parents with dementia are presented not just in light of how well-being is conceptualised, but also with a focus on the differences in the experience of care responsibilities between carer groups and how such differences can create barriers to well-being.

First, this chapter describes how the different carer groups experience caring for their relative with dementia. Second, an overview of the conceptualisation of well-being among family carers is presented. Third, key themes identified are outlined in light of carer gender, age and relationship to the care-recipient. Fourth, findings of this qualitative study are discussed with respect to the existing literature. Finally, the qualitative model of key aspects influencing carer well-being is compared with the conceptual model developed for this research.

5.1 The care experience

5.1.1 The male care experience

Husbands providing care

The seven husbands interviewed were the primary carers for their wives. At the time of the interview, the men in their 70s and 80s had all officially retired, however, two husbands retained links to their previous careers. Depending on the severity of their spouses' dementia, the men's care tasks did not just involve taking on primary responsibility for the organisation of the couples' everyday life but also the sole responsibility of maintaining the household, taking on financial responsibility and in most cases also supporting their wives with personal care tasks ranging from helping with dressing and make up to feeding and toileting. None of the spouses expressed the provision of personal care tasks as problematic, but instead as tasks that needed to get done. Husband 6 described how providing personal care, such as helping with going to the toilet, took both carer and care-recipient some time to get used to:

> *"I think we both felt a bit embarrassed about private things if you know what I mean. But now, she relies on me to help her and it's not embarrassed, just a chore to be done." (Husband 6)*

He also recognised that his age and being retired made it easier to take on the carer role. Acknowledging the provision of personal care for this wife in front of his colleagues would have been difficult in a male dominated work environment:

> *"If I had been working, I would have found it extremely difficult to admit to my work friends what I do. Putting make-up on my wife, helping her to go to the toilet, I wouldn't have liked to talk to them about that. But being retired I didn't have to tell anybody for I'd just go on and done it." (Husband 6)*

When discussing the husband's gendered experience of providing dementia care, some husbands referred to having acquired new skills. These did not just involve household skills such as cooking, washing and cleaning or doing the shopping but also taking responsibility of the couples' finances. Where couples previously had not shared household chores, husbands were happy to acknowledge their need to acquire these skills and also expressed a degree of pride when mastering this new field of expertise. While for some husbands it felt important to maintain running the household as their wives used to do, others were more selective in tasks they did not deem overly important. Husband 5, for instance, reported: '*The ironing board, I lost that yonks ago'.*

Sons providing care

In contrast with the husbands in this study, none of the adult sons supporting their mothers with dementia provided personal care for them. All but one of the men were retired at the point of interview and ages ranged from 50s/60s to 60s/70s. Sons in this study, and consistent with the previous research in similar populations, took on primarily care management tasks, such as organising their parent's finance and care as well as liaising with social services (Campbell, 2010; Grigorovich et al. 2016). Sons reported employment responsibility while supporting their parents as an important factor that limited their practical involvement:

> *"I'd go and see my mother, and then I'd go up to [airport] and get a plane […].. It's like quite difficult." (Son 5)*

One son, who experienced some temporary unemployment described that during this time it was easier for him to evenly share the care responsibility with his sister. The active involvement of women was also found in the cases of two other sons. Their wives were heavily involved in the provision of care for their mothers-in-law, accompanying them to the doctor, doing laundry and purchasing new clothes. The three

families provided and facilitated care in the community for several years. In these cases, sons frequently visited their mothers, provided reassurance, looked after their diet, and arranged for care services as needs arose. None of the sons resided with their mothers.

By the time of the interview all of these participants' mothers had moved into institutional care. One mother with dementia had recently passed away. Most sons tried to support their mothers' wishes to live independently in their own homes for as long as possible and only arranged for residential care once care needs exceeded the support that could be provided at home. Only one son viewed the provision of care in the community as an act of selfishness by the adult child that would draw other family members into a responsibility they otherwise would not voluntarily take. He emphasised people's individual choice to provide care. However, he also insisted that dementia care was so complex that ultimately other family members would feel obliged to support the main carer, even if they would not have chosen to provide care for the care-recipient in the first place.

5.1.2 The female care experience

Wives providing care

The seven wives interviewed in this study were the primary carers for six husbands and one female civil partner. The wives were in their 60s to 80s. Similar to the husbands, also wives reported taking on full responsibility for the couples' joint life. Only one wife provided personal care, the other care-recipients did not yet require such support.

Wives also took on responsibilities that previously their husbands carried as well as care tasks arising from their partner's needs. Examples included taking over financial decision making, accompanying the partner to medical appointments and managing the couple's social life. Out of the four wives reporting financial decision making to be a new responsibility, only one woman reported this experience as stressful but found help through a financial advisor. The other women were involved in the couple's financial decision-making prior to their partner's illness. The reference to financial decision-making among the wives tended to be voiced jointly with other responsibilities that now solely laid with the carer and therefore were used to express how the illness already at mild to moderate stages placed most of the responsibility on the caring spouse. In addition, some wives experienced behavioural changes in their husbands, which they found difficult to adjust to:

> *"I'm sure we've got a long way to go yet. But how things are in comparison, that was your original question, I have to do, it seems to me I have to do everything in terms of managing the household, managing financial affairs,*

plus I have to manage his financial affairs as well as the family financial affairs. I have to sort of deal with all the correspondence, I have to make all the telephone calls and receive all the telephone calls and be there whenever there's going to be, you know if we've got somebody coming to mend the boiler or, you know, anything where there's going to be some complexities that have to be understood. I have to be at every medical appointment […]. I'm saying this because actually it's all consuming." (Wife 3)

Wives, like husband carers, tried to maintain their partner's independence for as long as possible. This included giving their spouses responsibilities for certain tasks, such as washing up, or encouraging their husbands to go for walks.

Wife 6, whose husband had personal care needs, reflected on the difficulty of accepting her narrowing life. Similarly to husbands caring for their wives with greater care needs, she reported that she found it draining the way that he constantly followed her around, asking repetitive questions and wishing to help while being unable to perform the tasks. Sleep-disruption through nightly care needs and having to fight for some time for herself were additional burdening experiences. The negative impact of care responsibility on night-time sleep was also found in other research (Arber & Venn, 2011).

Daughters providing care

The care experience of daughters in this study is complex. Several daughters provided intensive hands-on care to a parent with dementia, including personal care for mothers and fathers at different stages of dementia, while some still carried responsibilities for their own children. By the time of the interview all but two fathers had been admitted into institutional care and one mother had passed away. One father who lived at home had a professional live-in carer; the second was cared for at home. Making difficult decisions, such as admitting the parent into institutional care, the family often left to the daughters who carried the main responsibility.

Several daughters found themselves caught between their own wish to care and parental and perceived societal expectations. Two daughters reflected on their caring responsibility as a role women in their generation were expected to take. Despite having fought for pursuing education and careers, they ended up giving up work to fulfil the role of the dutiful daughter. One daughter described almost *'feeling groomed to be a carer'.* Another daughter reported moving her family to a different part of the country to be able to meet the parental care demands. At the same time, daughters also expressed the wish to care. Feeling torn between their perceptions of themselves as emancipated

women and societal and personal pressures to take on care responsibility for their parents was difficult for some daughters.

All of the daughters had experienced several years of providing substantial care. In many ways daughters took on care responsibility similar to spouse carers while living away from their parents and also having to manage their own families. In their carer role, daughters took on various roles ranging from taking on managerial tasks of finding care support liaising with social services to dealing with challenging behaviours and taking on practical tasks such as managing shopping and medication similarly to those taken on by adult sons. Additionally, daughters provided personal care, or acted as mediators between their mothers and fathers.

Two daughters looked after parents who exhibited wandering behaviour, which meant frequent night calls and searches. Another daughter's father who had moved into the family home also required night-time attention. Disrupted sleeping patterns negatively impacted on the daughters' well-being (Arber & Venn, 2011).

On top of providing care for a parent with dementia, two daughters also had other care commitments. One daughter, who herself was in her 70s also supported other family members with whom she shared a house. The combination of this responsibility drew on her energy and health. Another daughter additionally supported her frail elderly neighbours and looked after another relative.

5.2 Carer conceptualising of well-being

In this section I describe how carers participating in qualitative interviews conceptualise well-being. During the interviews carers provided their personal understanding of the term well-being with respect to their carer role. Their answers included the absence of financial concerns, being allowed to show weakness, receiving attention and being looked after, experiencing happy moments and feelings of optimism, an overall positive state of mind, feeling empowered, physical components, having a network and place to relax, time for oneself and the ability to pursue own interests, eating well, getting a good night's sleep, peace of mind, security and experience being loved and loving (see Chapter 3.4.4). The most frequently mentioned components of well-being in carers' own definitions were physical and mental health.

I identified six components influencing carers' well-being from the interview transcripts: the relationship with the care-recipient, support from family and friends, safety and security of the person with dementia, successful use of coping mechanisms, external facilitators to well-being and carer health.

Figure 5.2 provides a graphical overview of how carers in this study conceptualise well-being and the factors that shape it. The carers' willingness to take on care for a parent or spouse with dementia is linked to the relationship with the care-recipient prior to the illness. Particularly among daughters and spouses, feelings of reciprocity were an important driver of wanting to take on care responsibility. Sons did not report this decision making process.

The interview narrative suggests that support from their family and friends was relevant to carer well-being in at least two ways. First, recognition by family and friends of the care they provided was important to carers' self-esteem. Second, practical support gave primary carers much needed respite opportunities. Obstructive support, such as empty promises or unwanted advice, on the other hand, had negative effects on carer well-being.

Care-recipients' safety was particularly important for spouses who themselves were elderly and felt at risk of experiencing health issues. Ensuring that their spouse with dementia would be looked after well in the event of their absence was important for their peace of mind. When organising such back-up mechanisms, spouse carers relied primarily on family and friends. Filial carers, on the other hand, reported to be concerned about their parents' physical safety and security when the care-recipient lived away from the carers.

Under the label 'successful coping mechanisms' I included the different strategies carers reported as useful in dealing with numerous stressors. Where carers knew how to respond to challenging behaviour or to relax at the end of a difficult day, this was conducive to their well-being.

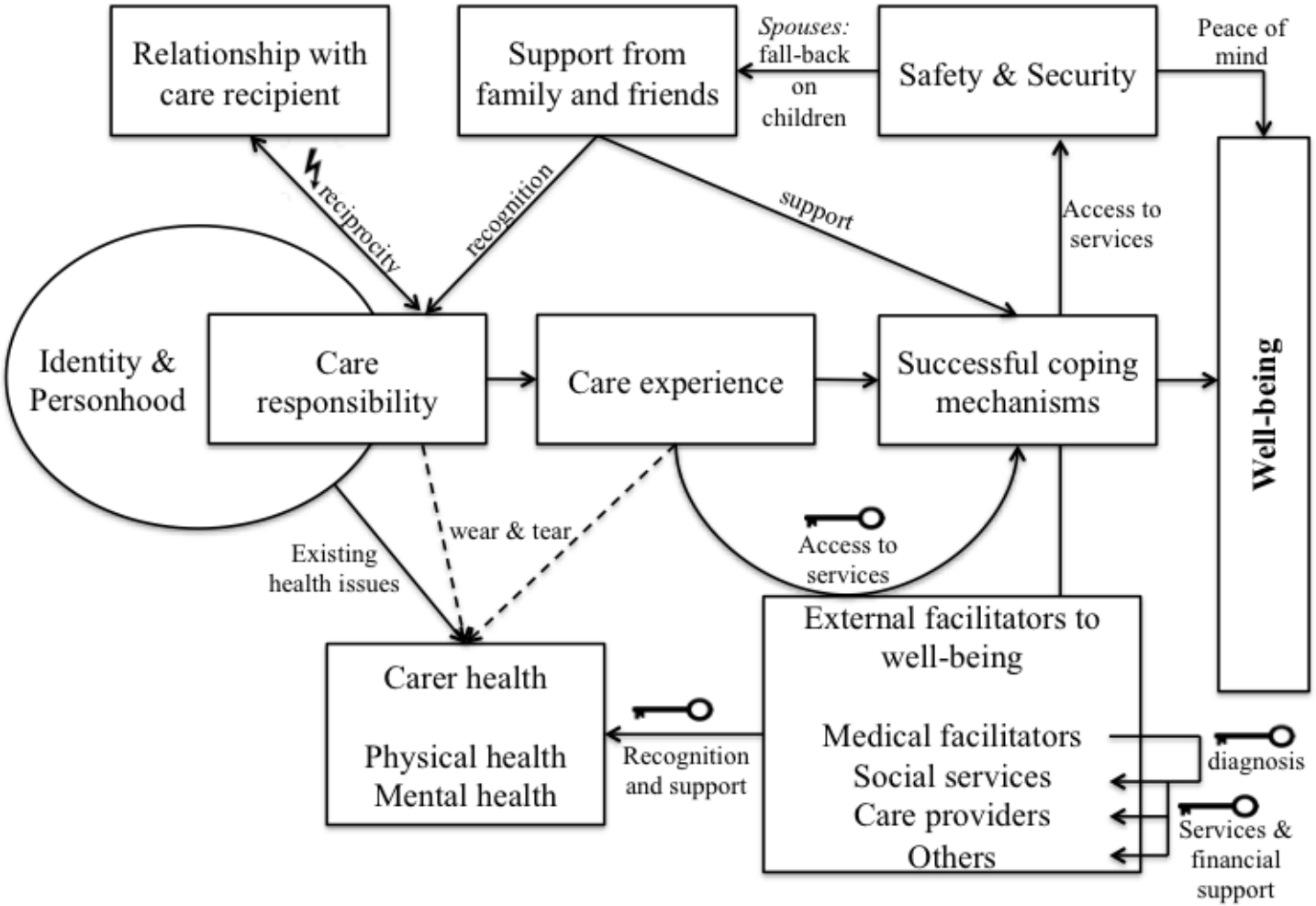
External facilitators to well-being included formal actors such as primary care doctors, social workers, home care providers or care home workers, but also people working for charitites or members of the community showing support for people with dementia and their carers. These external facilitators could directly provide services relieving carer responsibility but also unlock carer potential to employ coping mechanisms through the recognition of the illness and advisory and financial support. However, where formal actors did not fulfil the expected role or blocked access to services, they had a negative impact on carers' well-being.

The sixth factor was carer health. Most carers in this study were elderly themselves and experienced physical health problems prior to becoming a carer. Some carers also lived with pre-existing mental health issues. Participants reported that

everyday responsibility for a relative with dementia and the years of care provision additionally impacted on carers health.

Each of these factors will be discussed in detail in the next section.

Figure 5.2 Conceptualising carer well-being



5.3 Components of well-being

5.3.1 Successful coping mechanisms

Besides direct responses towards challenging behaviour, such as disrupting care-recipient's repetitive behaviour through reminiscence or other activities, carers developed techniques to support themselves in dealing with challenging care situations. Such self-care mechanisms helped carers to deal with challenging behaviour and hurtful experiences, for example experiencing verbal aggression by the care-recipient. One daughter reflected on protective behaviours acquired in her job. An important technique was to leave the 'black coat', as she described the experience of her mother's verbally aggressive behaviour towards her, before going home. For this she would often go and look at the sea and reflect on the day before returning home. A different method, described by a husband, involved keeping a written record of successful responses to his wife's behaviour, to which he could return when struggling to find solutions to newly occurring problems.

Besides immediate responses to challenging behaviours, spouses and adult daughters looking after their parents emphasised the importance of maintaining a normal everyday life for as long as possible. In line with mostly American literature, husbands in this study emphasised the importance of developing routines in their everyday life (Robinson et al., 2014; Black et al., 2008; Calasanti & King, 2007). Adherence to routines was found to reduce the risk of unforeseen events, which could cause distress and upset for the care-recipients; these were of particular concern for husbands**.** Unpredictable behaviour of their stressed spouses could in turn result in stressful experiences for the husbands:

> *"You just go day by day, you get up, do it, go to bed and then you just repeat it all the time. And once you get, you get into a routine, there's no two ways about it." (Husband 1)*

While such routines were also identifiable in the descriptions of care that wives and daughters provided, the women did not explicitly refer to setting up repetitive structures that provided assurance.

Maintaining joint activities with their partners was another important coping mechanism for spouses providing care. Carers emphasised the will to maintain activities enjoyed together throughout several decades of marriage. Spousal carers whose partners lived with milder stages of dementia were aware that future progression of the illness posed a threat to their social life and in several cases reported having to make alterations and

amendments to maintain their preferred lifestyle. Husband 1, for instance, reported how little alterations, such as buying a wheelchair, enabled the couple's ability to maintain everyday walks. Wife 5 illustrates well the experience of several spouse carers:

> *"[My wife] […] needs me there and like, when it's our turn […] on Sunday to do the coffee, she couldn´t do coffee alone anymore, you know, and she waits to be told everything, which is something I found quite difficult. But as long as I´m willing to take the initiative all the time she can do it all, so we actually still have a very full, interesting social life which we both enjoy." (Wife 5)*

With progression of the illness, spousal carers recognised a narrowing of the social lives as a couple. This effect has also been recognised in other research (Quinn, Clare & Woods, 2015; Gillies, 2011). The recognition that certain parts of the couples' joint lives had ceased were painful experiences:

> *"I like […] going on walks and there is a walk […], which I didn´t realise until we were half way through it that involves lots of very uneven, rocky steps and, I said well, it is clear from this experience that we won´t do this again. So that is something less, in a way that 'door is being closed'. But then you just adapt going on a more, and easier. You can go to the same area but an easier walk, so I got to, I do have to learn to modify things we have done in the past. So yeah, I think the idea of 'doors closing' is quite a good one actually. The options are fewer lets say." (Husband 4)*

> *"We used to do regular dinner parties […].. Parties – don't do any of that now. We can't do any of that because he used to share with that, and yeah, so that's gone […] – I've lost that – I've lost that part of my life." (Wife 7)*

When activities the couple used to enjoy together were no longer possible to pursue, some spouses found new forms of activities to maintain some joint social engagement by participating in activity groups, choirs, dementia-specific sport groups, lunch clubs or daytrips, often organised by charities (see Section 5.3.5).

Daughters also expressed a wish to engage in meaningful activities with their parent, such as playing games or taking the parent out for a day. They reported, however, that this was only possible when some of their responsibility for the parent was relieved, either through the presence of home care or by admission to a care home. One daughter described that only after receiving support from paid carers was she able again to engage in meaningful activities with her father. Being able to share some of the care responsibilities with paid carers meant that she could find quality in the relationship with her father again.

Another important coping mechanism was the carer's ability to find time for themselves. Across interviews, carers reported the need for time for themselves, to pursue individual activities and breaks from the responsibility of looking after a relative with dementia. Adult daughters particularly found it important to find time during which to pursue their own life, focusing on the relationship with their own husbands and children. Often this was only possible when other family members were able to take over responsibility for caring for the person with dementia:

> *"I mean, again it's been lucky that the children are grown up so […] [husband] and I can go out in the evening and say, just check [child]'s here." (Daughter 4)*

The ability to go on holidays also contributed to carer well-being. While some couples were able to continue their traditional way of holidaying together, others had to look to alternatives. Several couples reported that cruises, an option they would not have considered before the illness, were ideal since limited space on the ship and the entertainment provided was conducive to the independence of the spouse with dementia and allowed the carer time and space to pursue their own interests. At the same time spouses expressed caution, recognising that the progression of dementia may put a halt to the positive experience:

> *"A cruise went from [place], […] so we just get to [place] get on the boat and then she´s got fairly familiar surroundings and a room that she would get to know quite quickly and three meals a day and entertainment and all the other things and visiting the interesting places. So we did that and it worked very well. […] It may not work in a year or two but certainly at the moment it did work." (Husband 4)*

Similarly, filial carers reported that the ability to go on holiday with their own families was important to their well-being. Increasing parental care needs also posed a barrier to daughters' ability to get away. Only where suitable respite options were available and affordable could daughters feel in a position to go away. Only one son also experienced this barrier. For most sons, finding respite care options were viewed as a task rather than overshadowing the decision to go on holidays.

Husbands in this study were found to employ a fifth coping mechanism. Some husbands took on the role of advocates by lobbying medical specialists, volunteering as ambassadors, becoming involved as lay members of research reference groups and sharing their experience formally through presentations or informally by engaging on social media

platforms. One husband also took the initiative of informing managers of local bank branches about the needs of people with dementia and their carers. Female carers, on the other hand, were more reserved about sharing their expertise. Only one adult daughter who provided care for her parents for over a decade was involved in a network of family carers exchanging information and experience. Female expertise appeared to be shared on a more individual basis, such as with friends concerned about themselves or their partners.

5.3.2 Relationship with care-recipient and its impact on carers' willingness to care

Filial relationships

Among the 11 daughters and sons providing dementia care in this study, several filial carers reported good relationships with their parents before the onset of dementia. Three children did not particularly emphasise the relationship with their parents prior to the illness and few reported somewhat strained or distant relationships. Three daughters explained that their close relationship to their parent and the support they had received from them throughout their life were important drivers in their decision of taking on a care responsibility:

> *"But I've always had a really close relationship with my dad and he's a lovely chap and he's always been immensely supportive of me and you know, it's been a very close relationship. And so, I did feel that I wanted to look after him." (Daughter 1)*

None of the sons volunteered to express such specific thoughts. Instead, it became apparent that in most of the cases there were no other family members present or willing to take on the care responsibility. This suggests that while sons experienced responsibility towards their parents, their involvement was greatly determined by proximity, availability and need rather than the explicit wish to pay back for previous parental support. For instance, one son, who jointly with his sister cared for his parents, referred to his temporary unemployment as a reason for becoming more involved in their care.

A similar pattern was found when comparing adult children's current reflections on their parental relationship. Daughter 1 expressed how her father's inability to recognise her as his daughter was the final push in the decision of arranging for institutional care. This suggests that recognition of the relative providing care, and perhaps relatedly, the expression of gratitude and appreciation for the care provided can play an important role to the carer's willingness to provide care:

"And then, I think that's a major chang[ing] point when that [father stopped recognising daughter] starts to happen. Because, one of the reasons you're doing this is, this is your dad. […] And I think that you do, it changes the dynamic so much, it makes it a lot harder" (Daughter 1)

None of the sons providing care in the community, however, expressed a crumbling relationship to their parent as a breaking point in their ability to care. This may be due to the fact that most sons appeared to have reached limitations in the care they were willing and able to provide much earlier than daughters. As pointed out in Section 5.1.1, this may be due to the fact that none of the sons co-resided with their parents and – while trying to support their parent's independence – their ability to provide more time intensive care and supervision was limited. Furthermore, there may have been a generation effect around involvement in care as none of the sons reported providing personal care.

Spousal relationships

The majority of husbands and wives supporting their spouse with dementia reported being in good and longstanding relationships. Some husbands described how looking after their wives had brought the couples closer together again. Two husbands reported that their wives showed appreciation of the care they provided:

"I think our relationship it's always been good but we´ve got a lot closer. She does say to me at times, when we´re on our own, quiet and she´d say, "I do know what you do, I want you to keep doing it", "please don´t stop doing it". She obviously appreciates what I´m doing for her. It doesn´t come out very well sometimes, but it´s there." (Husband 6)

"We're still, well I still love her and all that sort of thing and got no inklings of anything else […]. So, and I think she quite often, says, sitting there, she says, 'I do love you'. And that come out as clear as day. […] Which is very nice, sort of brings tears to me eyes" (Husband 1)

While none of the spouses reported their relationship to be strained, a number of husbands and wives felt that the illness had taken away the person they shared their lives with. They could no longer consider their care-recipients as their partners. The experience of 'grieving for a former relationship' among spouses was also reported in other research (Clark, Prescott & Murphy, 2017, p.6):

"Yes, he's – oh – it's like Mummy and her little boy now." (Wife 6)

"Well, you couldn´t call it a loving relationship. She´s just stopped. Kissing or even hugging, just doesn´t bother her anymore. That´s what I´m saying, she´s

not the person I married. We had a very close relationship. But now it´s not, not really." (Husband 7)

The loss of a partner with whom to communicate was particularly present among husbands whose wives had progressed further in their dementia. However, the experience of loss could also be found among carers whose spouses had milder forms of dementia. Wife 7, for example, described how the illness caused a loss in characteristic attributes she always had valued in her husband:

"One of the things I liked about him when I first met him was his integrity […] and one of the biggest things apart from you know, loving him, was respect. And the snag is that it's really hard to respect somebody when they're not functioning properly anymore, and that's a great loss for me." (Wife 7)

Another important component of loss in spousal relationships was the cessation of the couples' sexual relationships. While some spouses reported that their sexual relationship had ceased already before their spouse's illness, others expressed experiencing great loss. Other studies report similar findings (Clark, Prescott & Murphy, 2017; Holdsworth & McCabe, 2018). Husbands, particularly, reported being sensitive about their wives' inability to consent to sexual activity. Some husbands, who reported their relationship as having grown closer, emphasised other forms of intimacy, such as hugging, kissing or holding hands as equally important as their previous sexual relationship and as beneficial to their well-being. Other research has reported similar findings (Davies et al., 2010).

5.3.3 Support from family and friends

Supportive family support

In all interviews, participants reported receiving practical and/or emotional support from their family members. Daughters and sons, whether or not their partners were present during the interview, particularly praised their respective spouses for all the support and understanding of the situation. The wives of two sons, who also were present during the interview, were heavily involved in the care provision and both couples seemed to view the provision of care as their joint responsibility. Other sons also reported their wives as offering important support in decision-making and providers of emotional support. Research using a Canadian sample also reported the importance of female support (Grigorovich et al., 2016).

Daughters also reported spousal support ranging from practical help with care, such as taking the parent shopping or driving round to turn on the television to forcing other

family members into taking responsibility to protect the daughters' well-being or taking early retirement when the daughter struggled with the care situation. The moral and practical support of their partners, as well as their understanding and approval of the care they provided seemed very important to the daughters:

> *"My husband said to my brother and my sister-in-law, 'You need to take charge of Christmas.'" (Daughter 3)*

> *"Last year, when I found it very difficult to cope, my hubby took early retirement, so he's now here during the day. And so, he's my best pal anyway, but yes, we now, that's our life. My hubby is here so I'm not alone, if you like." (Daughter 2)*

Other sources of support were carers' sisters, children, other relatives and close friends of the carer or the parent. While some daughters mentioned multiple sources of family support that would step in occasionally, only one son reported mutually sharing the care responsibility with his sister.

Three key sources of family support were identified for husbands and wives providing care for their spouses with dementia: children, friends and extended family. While most carers reported their children's awareness, understanding and availability when need arose only two husbands and three wives received regular practical support from their adult children. In only one of the five cases support was provided by a co-resident son:

> *"The youngest [son], who lives at home […] became a co-carer. So what happens is, that he looks after the house, and I look after [his] mum. And that works well." (Husband 6)*

Where carers' children, particularly daughters with their own small children, were recognised as a source of practical support, spouse carers expressed feelings of guilt about involving them in parental care. The perception that children should not be relied on due to their responsibility for their own families was also found in other research (Egdell, 2012):

> *"I went up to my old golf club […] a couple of days ago. And my daughter looked after her all day, which is not really fair on her cause she got a young family you know." (Husband 5)*

While a degree of support and understanding was almost expected from their own children, carers' expressed particular gratitude towards friends who recognised their need for support and a break from their everyday care responsibility. Husband 7, for instance, expressed great appreciation for the couple's friends who arranged weekly outings to the pub:

"And all of a sudden, a couple of months ago, [friend's wife] said, [friend] wants to take you down the pub. I said "what?" she said, well you always used to, she said. She says, "I can look after [your wife], you can go down the pub with [friend]. And that done more for me than anything. I said "[friend], thank you very much, this is what I needed". […] The best things have happened to me. I know it´s only a couple of hours every what, three four weeks. And I thought the world of that." (Husband 7)

Other carers did not feel in a position to leave their spouse, but reported regular contact to friends by phone as way to maintaining important relationships in their lives and beneficial to their well-being.

Other mostly emotional family support spouse carers received was provided by family members, such as the carers' brothers and sisters as well as their in-laws. Wife 7, for example, reported being able to confide in other female family members:

"I have got [family] who live fairly close by, and they always say to me, […] if you want to let off steam, we're here!" (Wife 7)

Only one husband received substantial practical support by his sister-in-law who regularly took his wife out. He was particularly surprised and moved by her support since the sisters were not particularly close prior to the diagnosis.

"But the biggest surprise it [wife]´s sister. […] Since this has happened, she's been absolutely brilliant. I think I would have needed help if it wasn´t for [wife´s sister]. It is because of her, mainly, I do get out." (Husband 7)

<u>Obstructive family support</u>

While most support provided by family and friends was greatly appreciated, obstructive forms of support - such as offering unsolicited advice or not providing the promised help - negatively affected carers. Two daughters reported such experiences. In the interview they expressed some of their frustrations:

"My brother had been spectacularly unhelpful really and in fact he used to make things so much worse, cos he was always on the phone sort of saying, well, why don't you do this and why haven't you spoken to this person and …" (Daughter 1)

"So, you know, everyone's trying to tell you what to do for the best: his friends are giving me inputs, and my brother's telling me I should be doing this, and I'm like, 'Whoa!'"(Daughter 3)

Brothers not providing their share were a source of disappointment for daughters. Despite feeling left alone with the care responsibility, daughters found reasons for their brothers'

behaviour. Gendered upbringing, job responsibilities and personal circumstances, were reasons daughters brought up to defend their brothers limited activity.

Further sources of disappointment were family members who showed no interest and refused to take on the responsibility the carer was hoping to share. One husband, for instance, described his difficulty in accepting that his children did not want to get more actively involved in supporting their parents. While justifying their distance, he found it difficult to accept when their daughter did not want her parents to be moving closer to her. Particularly interesting was the gendered expectation towards the daughter, and the recognition that had she not been as successful in her career, she might have been more available to provide support:

> *"There is one of these care home companies that does a really nice development […] where our daughter is. […] And we did look at those and we said to our daughter we're thinking of moving to this development […]. She said, "why would you wanna do that?" We said, so we could be near you, we can be. She said "no don´t do that. […]" So that was a thumbs down […] and she was very definite, that would be a bad idea. And also realistically, she said, that mainly we´ve got all our friends here, going somewhere where we´d got no real link with at all. She´s got her own networks there, but we haven´t. So that was quite interesting." (Husband 4)*

> *"The daughter is in [town far away], she is [working], so she again is very very busy. […][We are] very proud of our [...] children, all doing interesting [things] but they haven't got the sort of time or commitment and with a lot of daughters [that] take on this caring role if they are around the corner working in the local supermarket [it] is probably easier than if they are [working in other jobs]." (Husband 4)*

Relatedly, Husband 1 expressed frustration that a relative, who used to regularly take his wife out, withdrew from doing so when the dementia became more apparent.

5.3.4 Safety and Security

Ensuring safety and security of the person with dementia was another key concern of carers. It was interesting to note that concerns of spouses and adult children were distinctively different. Spouse carers, often elderly themselves, were aware that the couple's functioning depended entirely on their own physical and cognitive abilities:

> *"Because my biggest fear – and you must also be sure to ask carers this – is what happens if something happens to the carer? You see, I am able to keep the ship going quite easily because I'm well, I'm fit, there's nothing wrong with my*

memory or my ability, and I run the whole thing; the finances, the doctor's appointments, the shopping, whatever we do […], but if I weren't here, or if anything happened to me, then my wife would be in trouble." (Husband 3)

Two spouse carers reported that they found it conducive to their peace of mind to make arrangements for those taking over in an emergency situation, such as preparing written information regarding access to finance and personal wishes for care.

Daughters, on the other hand, experienced greater concern about the physical safety of their parent living independently. Daughter 1 described how the constant concern for her father has affected her well-being:

"I am slightly anxious, I´ve never been much of a worrier, really, and I feel that these last couple of years have sent me in to being a worrier. […] And I feel that has been engendered by the sort of situation of the last sort of […] years, and I don´t want to carry on, I want to go back to not being a worrier." (Daughter 1)

Spouses also recognised potential safety hazards in their everyday life, but since all couples in this study lived together, the magnitude of such concerns was much smaller. Two husbands explained how moving from their own homes into residential care settings enhanced the couple's safety and reduced risks.

5.3.5. External facilitators to well-being

As mentioned above, a number of actors outside the internal circle of family and friends played crucial roles when conceptualising carers' well-being. In this analysis external facilitators to care have been grouped into four categories: the medical profession, social services, care providers (home care and care home) and other services (including charities).

In the process of accessing these facilitators, a hierarchical image emerges. First, without the recognition of dementia by the primary care doctor, carers are unable to unlock the ability to access social services. Diagnosis is key. Second, social services are important service providers and, once an individual's financial reserves are depleted, they maintain funding for care. While carers can access care providers directly as long as sufficient funding is available, social services become key providers once resources run dry.

Similarly other service providers such as charities are potentially directly accessible by carers, but often carers rely on the medical profession and social services to point them in the right direction:

"I would say, really push the doctor for help. Not just the diagnosis but for the help and support which is – because you have to go through the doctor to get social services" (Wife 2)

Medical facilitators

The role of the GP and psychiatrist in diagnosing the person with dementia was considered as a crucial step by most interviewees. Female carers particularly emphasised the importance of a diagnosis and the subsequent access to medication, not just for the purpose of recognition of the issues carers were dealing with, but also to unlock access to social services.

The importance of the recognition of dementia by the GP became particularly evident when looking at cases where the GP did not immediately get on board. Among the interviewees in this study only female carers reported experiencing difficulties in obtaining a diagnosis for their relative.

Three daughters and two wives shared their frustration about their concerns not being recognised. One daughter acknowledged that it was probably due to her persistence that her father was diagnosed after one year of requests. Another Daughter voiced her regrets at not having sought out a second opinion, as the refusal to assess her mother inhibited her ability to access help and support available. Three wives experienced a lack of interest in dementia by their general practitioners but expressed concern about potentially adverse consequences by changing doctors.

Most husbands as well as one daughter, on the other hand, praised their primary care providers as they did not just deliver a diagnosis and look after the physical health of the care-recipient but also recognised the carer's need for support and acted on that by connecting them with social services, carer groups and charities, advised on Power of Attorney and advanced directives. They also checked on their personal well-being. One husband, for instance, described his wife's GP as not just asking about how he was holding up, but also suggesting that he looked for respite options as the GP recognised growing care demands.

For the carers it was important to be considered a partner in the medical dialogue. Filial carers especially noted breaking the barrier to medical information as important. Two sons and a daughter-in-law described how their parent's GP supported them by providing explanations on the trajectory of the illness and by keeping them informed about what was happening:

"You need a bit more medical advice just to know what to expect, why it´s happening, why the person is reacting like they are" (Son 5)

"If it´s a parent or a son or daughter then go to their doctor and ask if you can be treated as, you know, as a third party. Because that was the first step, cos you´re sort of thinking oh what am I gonna do? That was what I was worried about." (Daughter-in-law 2)

Spouse carers reported even more active involvement, such as monitoring the effects of medication and liaising with the doctors. Where primary care physicians were knowledgeable about the specific needs of people with dementia and recognised the carers as partners in looking after the care-recipients, it empowered carers and enhanced their well-being. Where physicians blocked a diagnosis, carers were limited in their access to other support and felt stranded and isolated:

"My wellbeing started to go downhill as regards my mother when I felt helpless, and I would have liked to have felt that there were plenty of people in the GP Practice, social services, the people you expect to be able to help you, and they weren't, and that's when I started to feel helpless." (Daughter 6)

Social services

Social services were a second important resource, frequently triggered by medical professionals following diagnosis or the recognition of needs. Among participants in this study, the triggering mechanism only appeared to have functioned for spouse carers. One wife and two husbands were put in touch with social services following their partners' diagnosis. Also in the cases of two other spouse carers, doctors recognised the need for support and informed social services. Subsequently the carers received an assessment and the provision of services:

"Didn´t seem to get much help and then we saw the [specialist], a regular visit and I said "isn´t there any help available?" "Where do I go to get some help?" and he said "I refer you to the local […][department] and somebody there will put you in the right direction, which happened. And it was the […][department], the [specialist] there. That, on our first visit. 'What help you´re getting?' 'None'. 'Alright, you want that one, you want that one, you want that one'. Within days people were phoning me up, we had the [local] council there, […] they come out and do an assessment of safety in the home" (Husband 6)

Another husband and two wives were also in contact with social services but did not describe how this contact was initiated. The data suggests that once spouse carers were put in contact with social services their experience was overwhelmingly positive.

Filial carers, on the other hand, drew a very different picture. Among the nine sons and daughters describing their experience with social services only two sons and one daughter shared positive experiences. Three daughters and one son, on the other hand, described that their experience with social services in many respects added to the burden rather than provided constructive support. In their critique, carers expressed feeling helpless when their requests for support were dismissed, in particular where the care-recipient had no more financial means to cover for the expense of care and the carers felt overwhelmed with the responsibility:

> *"And in fact actually we then, eventually, we managed to get social services involved. And that's been my biggest problem the last, this last year, year and a bit It's just dealing with social services which is just such hard work. So frustrating. Because we wanted to get things like respite care." (Daughter 1)*

Another daughter expressed her frustration about the fragmentation of services, describing how she went through multiple assessments by different parts of the organisation without any real outcomes. Her situation was particular difficult, as she also supported other family members. Attending meetings required managing her other responsibilities. Her wish was one point of contact that could point carers to the different services available to them. The need for a one-point contact was also expressed by two sons and a daughter as well as voiced by carers in a similar study. The wish for 'a named individual or team to act as a key worker or case manager' as a direct contact was also found in research on carers supporting people with severe and complex needs in England (Gridley, Brooks & Glendinning, 2014, p.594):

> *"I'd go through the same procedures about filling in boxes and ticking this and signing that, and being given leaflets about we can do this and that, and all these smiling people all over these leaflets, about how wonderful dementia is, and then off they go, and what do I do? They never gave me what I needed. […] And I filled in the form and I said what you need is a one-stop shop where I can say to somebody; this is our situation and which of these organisations is going to actually help us? Because there's no point one after the other visiting, seeing the same situation, time after time after time, and then not helping us. I mean, occupational health were good in that they were able to provide [tools], but that only kept us going for another six months. So, you know, I mean everybody was so nice, and they – you know, they've all got these – what they think are offers […]. I have a magazine that comes regularly – […] and it talks about, 'come for a chat and a coffee morning […]'. How am I going to do that? You know?" (Daughter 6)*

Six interviewees described being in contact with a social worker. One husband, two sons and a daughter described positive experiences. In these cases social workers arranged for day care options, facilitated access to home care and supported the transition into institutional care where it became necessary. Two filial carers particularly emphasised how important their social workers were not just in facilitating their parent's care needs, but also in improving their ability to deal with the care responsibility:

> *"If you're on your own dealing with it, you just get on with it, basically, because you have to really. You can't do lots of other things can you? I mean, it has to be dealt with but without the support of social services it would be a lot harder. I mean, [social worker] was just such a – you know, he was a brick – just such a rock for me." (Son 5)*

> *"I did ring [name] a couple of times and I said 'look I'm sorry, [name], I've just got to tell you what sort of night I've had.' And I said 'you don't have to say anything, I'm gonna read these out to you.' I said 'you don't have to explain it, you don't have to justify it' I said 'I've got to read these out to you, I've got to pass them on to somebody.' I said 'cos I can't sleep on this one.'" (Daughter 5)*

Another son, on the other hand, expressed his frustration about a lack of communication. He described how, on the one hand, he was expected to take responsibility for his mother's needs while, on the other hand he was not being informed about decisions made on her behalf. Another son also expressed his discontent about how he felt pressured into finding long-term accommodation for his father a few days after he had been admitted to care, while still having to look after his mother. At the same time, Son 4 recognised the commitment of someone who went beyond official guidelines to support the family in finding suitable accommodation:

> *"We had a [someone] come out […][to meet] us because we said, look, we really don't know what we're looking for, and [person] he was absolutely brilliant. [Person] said look, here's a directory that you can have. [Person] said I'm not allowed to recommend anything to you but you'll notice I've highlighted certain places where – that may be helpful. […] That saved us days and days. I mean, it took us a couple of weeks to visit all the various places […], to come to the decision, but without that again, I think we would have been at a complete loss." (Son 4)*

Despite frustrations with the organisation and availability of social services, all filial carers in this study expressed their understanding that social services are under great pressure and had to make decisions based on people's needs. Out of such recognition carers

overwhelmingly did not attempt to access services unless they experienced great needs. Where services were initiated and provided, carers expressed appreciation and gratitude towards the system and the individuals who were providing support. In cases where needs for practical and financial support were dismissed it left carers stranded and negatively affected their well-being.

Others service providers

Other forms of support services, such as the provision of day care and other forms of respite, joint activities for the care dyad, carer groups and support workers as well as information on the illness were provided by charitable organisations. These organisations played an important role for spouses providing care. Participating in joint activities enabled spouses to maintain their everyday life as couples. Respite care opportunities, including day care and activity groups for the care-recipient gave carers time for themselves, and so were vital facilitators for carer well-being as discussed in Section 5.3.1. In this study, three husbands and one wife who currently cared for their partners with moderate to severe dementia reported the use of day care. Some of the filial carers had arranged day care opportunities for their parents while they lived in their own homes.

Activities offered to the care dyad or solely to the carer enabled knowledge exchange and offered carers the possibility to unburden. Carer groups, for example, were particularly popular with spouse carers. Three husbands as well as three wives found participating in these groups beneficial as it enabled them to share their problems but also to gather specific advice from invited speakers:

> *"Where I go once a month to a support group […] and that is brilliant because there is [a number] of us normally all carers, all unpaid carers, mostly women, all their husbands have got the problem. But to share, I mean, you don´t have to say anything if you don´t want to but everybody shares, what they´ve been going through and it is, well it isn´t rewarding really, […]. So that´s good for me." (Husband 5)*

In the literature it has been reported that male carers tend to avoid support groups (Pretorius, Walker & Heyns, 2009; McDonnell & Ryan, 2011). While men in this study recognised that most other carers in the group were female, that did not distract from their beneficial experience and suggests that for these carers there were no issues with their concept of masculinity. Two husbands in the study, however, conformed to this gendered

perspective. Husband 4 explains that he took a backseat with an online carer group as he found the experiences shared between women too harrowing:

> *"I joined a […] support group which is a [social media] group and I would say virtually all of the people on that group are women. I know it's gender stereotype but they tend to like communicating with other women looking after husbands who have got [dementia] so that's and I sort of taken a backseat with that group because it seemed to be first of all a lot of very bad news. […] And I don't really want to know that. I know that could happen at some point but it's not at the moment. And also, you know on [social media] how you get comments. Someone to say "I feel very guilty, I've left my husband in a nursing home for the night I'm going away on a holiday […]". So then you get ten people to say, "you are quite right, you deserve a reward, you deserve a break" and all this. I think it was very gender specific, I don't think men, I don't think a male group would act in the same [way]. They would mutually support each other." (Husband 4)*

Similar concerns were also raised by Wife 7, putting a question mark on whether the avoidance of harrowing experience should be claimed as a purely male coping mechanism:

> *"I am constantly being told why don't you? But, if I joined a carer group I think mostly I would probably find that everybody else was far worse off than me and I don't think I need that. I think I'd rather not know how worse it could be!" (Wife 7)*

Again, contrary to evidence from the literature, the only filial carer who actively sought support from a charitable organisation was male. While overall uptake of support of resources provided by charities was low among filial carers, only Son 4 turned towards charity support:

> *"So I contacted the [organisation] and rang up to ask for support and they got back to me and said, it's for your [parent] – you want us to visit your [parent]? And I said no, I want you to visit me and my sister. They hadn't actually done that before but the woman that came up, she was absolutely incredible. She realised what we were going through, we met probably monthly, and what she would do was she would explain to us any questions obviously we needed answering, but she also helped us to focus on what we needed to do first, to prioritise the concerns we had and the issues. She also gave us tips to watch out for, and places to go for further support and that was incredible." (Son 4)*

Home care

Some filial carers in this study brought paid carers in to support them with looking after their relative. None of the spouses had arranged home care despite several care-

recipients experiencing great care needs. Two spouse carers stated that their partners did not want to receive home care. Husband 2 expressed the expected inflexibility of such services and his preference for maintaining their routine:

> *She does not 'want a teenager, […] [she does not] want a stranger in […] [her] house' (Husband 4)*
>
> *"She said well they wouldn't get here till half seven, eight o'clock. I said 'well, that's no good'. Not being horrible, I know they wouldn't be there then, because [wife] is out of bed then […]. So, I couldn't make her stay in bed to wait for the carer to come. I don't mind doing it, it don't bother me at all." (Husband 2)*

Three daughters and two sons used paid home carers. Three daughters and one son were satisfied with the care they received for as long as it was suitable. Two of the daughters only expected certain tasks at specific times of the day, such as dressing in the morning and the provision of meals, to be handled by the carers. The carers who came to support the family impressed one daughter, whose mother received palliative home care. Son 3, on the other hand, was disappointed by the care his mother received from the different care companies the family employed and expressed his frustration about the lack of continuity, which he emphasised as particularly important for someone with dementia:

> *"Carers turning up, leaving her to go on to something else and coming back; leaving her with – giving her cold food – we had an occasion where a carer turned up and [mother] phoned up and said, 'I can't eat this, it's stone cold.' We went round there and the food was stone cold. She got it straight out of the fridge and gave it to her – didn't even heat it up. We've had occasions where they haven't turned up, or they've been an hour and a half, two hours late, and [mother] near the end wanted to go to bed [early]. If they didn't turn up she was panicking. She was in tears, we had to go round all the time because you couldn't leave her, cos she knew that she was supposed to be going to bed, no-one was there, was anybody gonna turn up? Are they gonna forget me? You know, it's a horrendous situation. […] There's no continuity of carers, there's no continuity of time. Some days they would get her up at quarter to seven in the morning, seven o'clock in the morning, another day you'd get the rota and see they're not gonna get her up til 10 o'clock. You can't expect somebody with dementia – and other problems […] – you can't expect people like that to stay in bed, because they don't understand. You know, so there's no continuity. Would you want to get up at 7 o'clock and 10.30 the next? You can't live like that. Same with going to bed. Would you want to go to bed at 7 o'clock one day and 9.30 the next? You must have continuity." (Son 3)*

Two daughters raised similar concerns to the experience described above. Due to their low expectations towards care agencies, the women decided to organise their fathers' care differently. One daughter independently hired two paid carers with whom she built a little care team. Between the three of them the women rotated their duties, which enabled the daughter to be involved in her father's care while also being able to take time off. Carers and care-recipients in the study by Gridley, Brooks and Glenndining (2014) also emphasised the importance of familiarity with home carers and their understanding of the care-recipient's specific care needs:

> *"And I also felt that I could trust them. And I liked them and I felt that dad liked them. I also learnt quite a lot from them about how to care for him." (Daughter 1)*

One daughter, who was concerned about her father not accepting incoming female carers, found a male live-in carer. His presence enabled her father not just to stay in his own home but also to continue pursuing an active life while leaving the children assured that he is being looked after:

> *"But my Dad still does – he still goes to [watch sports], because […] the carer, he is wonderful! He is sports-mad. He has actually – he's changed all our lives because he makes it so much easier for us to go and visit Dad. The pressure is off. And also we are still visiting Dad in his house, so he's happy being in his house, and he's just accepted that [carer] is part of the furniture now." (Daughter 3)*

Knowing that their parents were safe and well looked after was important to all filial carers. Concerns regarding the quality of care received negatively impacted on all carers, while the assurance that their parents were not just kept safe but cared for helped to relieve some of the burden and worries filial carers experienced and positively contributed to their well-being. In the context of exploring care arrangements preferred by carers and people with dementia, such as live-in carers or home care services, it is important to note that these options may be more limited for families with low income. A recent report by the Alzheimer's Society (2018) highlights the implications of reduced availability of financial support and services provided by social care services on families supporting a relative with dementia.

Institutional care

At the time of the interviews, all but two parents with dementia had moved into residential care. All spouses with dementia were looked after in the community. In three cases, moving a parent into residential care was facilitated by social services, as the care-recipients' resources had been used up. As discussed above, recognition of needs for filial carers was not always easy to achieve and brought considerable stress. Once the parents had been moved into care, however, two daughters expressed that knowing their parents were looked after around the clock in the care home improved their well-being:

> *"I'd like to have got to this point sooner, with my mother being in the nursing home. So my wellbeing would have been if the situation I found my mother in hadn't taken so much out of me." (Daughter 6)*

Son 5 also concluded that his well-being improved when his mother was admitted into institutional care:

> *"I think I would have been stronger and not let my mother have this wish to stay at home […]. I was doing what she wanted, not doing what the best thing was for all of us really. […] I mean, it might sound callous, but it's not to be callous, but once the person is a home then it takes an awful lot of the responsibility away from you. Because I was still fussing and bustling when my mother was in the home, one of the women said to me […] look, it's not your responsibility any more. Stop worrying." (Son 5)*

The daughters and sons whose self-funding parents were admitted to care once resources in the community were exhausted made similar remarks. Nevertheless, all filial carers but one son tried to obey their parents wish to age in their own home. He argued that sending his mother into care immediately after her diagnosis enabled her to settle and to enjoy the entertainment offered before the dementia would take away this ability:

> *"And therefore, the sooner you get them into a home, the sooner they will be able to settle and they will join and that will become their home. The longer you leave it, the more alien going into a home will be and they won't have the opportunity to, you know, share in the activities, get to know the other people. They will be the outsider and they'll just sit there in their armchair" (Son 1)*

For none of the carers was the decision to move their parent into a care home taken lightly: several carers expressed guilt over this decision:

> *"Daughter-in-law 2: But there's a terrible feeling of guilt when you first put them in home.*
>
> *Son 2: Oh, massive yeah."*
>
> *"She always said I never want to go into care. I never want to go into a home. But it gets to a point where somebody's got to make a decision, and I feel so guilty about that, even now. […] That I've had to go against her wishes." (Son 3)*

Furthermore, while all carers acknowledged that admitting their parent into institutional care was a relief, some carers expressed difficulty with letting go of the responsibility. While their everyday care responsibility had ceased, it was important for filial carers to monitor the quality of care their parents received and to intervene where they felt that this was not the case. Experiencing less than the expected quality of care detracted from carers' well-being.

Another concern for relatives of self-funding care-recipients was awareness that once the money ran out the parent with dementia would have to be transferred into a care home accepting social services funding. Filial carers were particularly worried about the quality of care their parents would be receiving in institutions approved for social services funding. For Daughter 2 this concern was strong enough for her to continue to provide care to her father at home despite the fact that his intense needs for care and supervision made it almost impossible for her to leave the house:

> *"I think I've now seen most of the homes in [area] which take the government fee and I don't want my dad there. As much as I don't want him here, I don't want him in one of those homes either."(Daughter 2)*

All but one son experienced the transition from community to institutional care as a difficult step that was only undertaken when carers' and service resources were exhausted. Looking back, however, most carers felt that being relieved from their sole responsibility and being able to pursue their personal lives again had a major impact on their well-being.

5.3.6 Carer health

Male and female carers of all age groups reflected on physical and mental health as important contributors to well-being. While two husbands equated well-being to physical health, other carer groups viewed physical components as underlying factors, but gave more weight to aspects of mental health. A number of male and female carers experienced existing health issues; others started experiencing physical and mental health issues while providing care. Elderly spouse carers particularly described having experienced heart

attacks, strokes and cancer in the distant and recent past. Wife 5 and Husband 3 reflected on the importance of physical health as part of their well-being, not with respect to the absence of physical ailments but in terms of their ability to pursue their everyday life:

> *"Well, I suppose it does mean having physical health to start with, so that I can do what I want to do." (Wife 5)*
>
> *"Suppose if somebody said, how do you rate your wellbeing, I'd say, oh, 6 or 7 out of 10 or something like that you see. Otherwise I'm generally a good healthy outlook on life, you know, apart from the obvious things you have to do like wearing your hearing aid, wearing glasses […]and I think the basic sort of measures of good health are there. I can run around and do my dancing and you know, things like that, so I think are good wellbeing." (Husband 3)*

While the spouses recognised these health issues as relevant, the overall message was that these problems were manageable. Their partner's needs were more pressing:

> *"But it´s something I have to put up with, but yeah it´s difficult. Some days are so painful. I´ve got painkillers that I take but they send me a bit into space. [laughs] But I try not to; you know I gotta keep going. I try not to think about it too much." (Husband 6)*

A number of spouses and filial carers also reported mental health issues. In contrast to physical health problems which often were brushed aside as manageable with a couple of pills, carers reported attending to their mental health needs as more relevant to their everyday ability of handling care. One husband reported how his family picked up on his snappy, uptight behaviour after taking on the care responsibility for his wife, following which he sought help:

> *"I was very snappy, very on edge and my wife […] comes from a big family […]. And they all remarked to my [children] "your dad´s a bit uptight. What´s the matter with him?" you know." (Husband 6)*
>
> *"I feel a lot more confident. I can handle most things now. Occasionally I get a thing, dropped in my lap, I panic a little bit but I think that´s probably human nature". (Husband 6).*

Also one son recognised how the experience of supporting his parents with dementia caused painful tensions in his legs, which ultimately were diagnosed and treated. The recognition of mental health issues in men in this study was rather different to those of

women who expressed more traditional symptoms, such as lack of energy, difficulties with sleeping or feeling anxious.

Two wives and one daughter reported their eligibility for counselling and the tremendous benefit they could draw from the availability of these resources. Both wives mentioned the financial aspects with regards to access to therapy. One wife reported not being able to maintain this kind of support due to the high costs, while another wife used her carer allowance to purchase the service. Also one daughter, who received some counselling when struggling with the care situation, voiced monetary concerns. In her case, however, she struggled with guilt from being provided with such a service while feeling that other people may be in greater need. The recognition and management of physical health aspects are important components in enabling carers to support their relatives with dementia. Several male and female carers of varying age have experienced mental health issues as a consequence of care.

5.4 Discussion

5.4.1 Differences and similarities in the experience of care and the conceptualisation of well-being

The findings show that carers experience a range of inter-related factors as influential to their well-being. Due to different care experiences among the four carer groups, there was considerable variation in how the six key factors identified as influential to carer well-being interacted. The people with dementia supported by husbands, daughters and sons in this study had more advanced forms of dementia than those supported by wives, and therefore generally had greater care needs. Husbands and daughters provided intense levels of care and support. Sons, on the other hand, while actively involved, took on predominantly managerial approaches. Most received substantial support from a wife or sister, social services and paid care providers. The receipt of support from the sons' partners and from formal support services was also reported in other research (Campbell, 2010; McDonnell & Ryan, 2014).

In their caring style, sons were protective of their own lives and limited personal involvement so that it would not affect their ability to pursue paid employment, hobbies or their ability to look after their own family. Where sons became more actively involved in parental care, there always was a woman (wife or sister) supporting them. The managerial approach observed particularly among sons but also among some husbands in the literature

is frequently associated with men (Black et al., 2008; McDonnell & Ryan, 2014; Grigorovich et al., 2016). Robinson and colleagues (2014, p.419) argue that associations with professional roles 'reaffirm their sense of masculinity' in a female-dominated role.

Daughters, on the other hand, were more involved than sons in the provision of personal care (see also Chapter 7). Carrying everyday responsibility for their parent's care needs made it more difficult for them to protect their own lives from the demands of care. While daughters often reported the wish to care, they struggled in meeting both the demands of their parent and those of their own family.

Relationship with care-recipient

The reported nature of the relationship with the care-recipient appeared to be largely determined by the relationship prior to the illness, the feeling of reciprocity and recognition and appreciation of the care provided. This pattern was particularly observable among husbands, daughters and wives. In this context reciprocity refers to the carers' desire to give back for the years of care and support they received from the care-recipient (Quinn, Clare & Woods, 2015; Lewinter, 2003; Gillies, 2011). Where reciprocity was a motive to provide care, carers experienced difficulties when the initial relationship broke down due to changes in the care-recipients' character and advanced memory loss, including memory of the relationship to the carer and therefore the care-recipient no longer being able to return even small reciprocal gestures. On the contrary, where husbands reported their wives' appreciation of the care and support they provided, this brought the couples closer together and enhanced husbands' willingness to provide care. Similar findings were reported for both male and female carers in other studies (Hasselkus & Murray, 2007; Monin, Schulz & Feeney, 2015; Quinn, Clare & Woods, 2015). However, Winter, Gitlin and Dennis (2011) found that men's willingness to care was more strongly affected by the relationship quality with the care-recipient than women's.

Sons did not specifically report these aspects, but instead took on care responsibility where no other unpaid carers were willing or able to take on the care responsibility. Some sons in a Canadian study reported similar motivations (Grigorovich et al., 2016). Others, however, emphasised relationship bonds and feelings of reciprocity similar to husbands and daughters in this study (McDonnell & Ryan, 2014; Campbell, 2010). These differences in findings might be because carers were not explicitly asked in the interview about their motivations to care.

Wives, on the other hand – and similar to most carers in this study - reported to have had a good relationships prior to the illness, did not report their partners acknowledgement, recognition or gratitude in the way that husbands in this study did. Instead, some women compared their situation to that of motherhood, which perhaps lowered expectations of gratitude and appreciation. The comparison to motherhood among female carers of people with dementia was also reported in a German study (Toepfer, Foster & Wilz, 2014).

Successful coping mechanisms

Out of all the coping mechanisms it was most important to carers to be able to find slots of time to pursue their own interests. Husbands overwhelmingly employed these mechanisms successfully. Wives, even though the people they supported had less advanced forms of dementia, reported difficulties with finding time for themselves due to their husband's needs for support. Reduced opportunity to pursue their own interests detracted from their well-being and is consistent with findings suggesting that women experience the provision of dementia care as more burdensome than men do (Friedemann & Buckwalter, 2014; McDonnell & Ryan, 2011; Sutcliffe et al., 2017).

In many ways daughters' care experiences were more similar to that of spouse carers than to adult sons. Substantial care involvement led to daughters using similar coping mechanisms as spouses. While daughters expressed the need for time for themselves and their own family, most daughters were only able to take breaks from the care responsibility or to go on holidays when replacement care was available and affordable. This is consistent with Eriksson, Sandberg and Hellström's (2012) findings that women tend to prioritise their caring duties over their own needs. Ensuring that in their absence their parent with dementia was looked after in a caring environment was a great concern for daughters, while most sons in their managerial efforts did not put the family holiday in question. Similarly, a Spanish study showed that low uptake of leisure activities among daughters is associated with greater experience of guilt and higher scores in a measure of depressive symptoms, and a Canadian study described the setting of boundaries as a coping mechanism employed by sons (Romero-Moreno et al., 2014; Grigorovich et al., 2016). Only one son and his wife, providing and managing care in the community, reported being unable to go away. In the literature, this experience was typically associated with the adult sons being single and living with the cared-for person (Campbell, 2010).

Support from family and friends

Spouse carers predominantly provided care by themselves, relying on their coping mechanisms and support from family and friends to maintain their well-being. Husbands and wives reported receiving emotional and practical support from their children. In this study, husbands appeared to have a greater active support network than wives, with friends playing an important part in providing respite opportunities. Despite husbands overall receiving more practical support, men expressed greater disappointment when their children and other relatives from whom they expected to receive support did not fulfil these expectations. Wives did not make such remarks, perhaps due to lower expectations of such support.

Filial carers reported receiving important support from their spouses; this was also found in other research (Edwards, 2014; Grigorovich et al., 2016). Sons, apart from one son who shared the care responsibility with his sister, did not report a wider informal support network. Several daughters, on the other hand, referred to their own children, friends and other family members as supportive to the care situation. Where such support was available daughters recognised and valued it.

Some daughters also experienced obstructive family support. In particular, brothers providing unsolicited advice were a source of irritation. It was interesting, however, that in all situations where such disappointment was expressed, daughters also delivered an explanation for why their brothers may have acted in such ways. Empty promises and unwanted involvement from family members and friends of the family were another aspect detracting from daughters' well-being.

Irrespective of carer gender, constructive and positive support from family members and friends contributed positively to carers' well-being, obstructive behaviour detracted from it. In line with these findings, an American study reported that where family contribution was perceived as adequate, it was associated with less carer distress (Ashida, Marcum & Koehly, 2018). In addition, Chappell and Reid (2002) found that perceived social support directly influenced well-being. This study also reported that carers of people with 'greater physical dependency tended to receive' more social support (Chappell & Reid, 2002, p.777). This would be consistent with findings in this study, where husbands' supported spouses with more severe dementia than wives' (see Section 5.1.2). On the other hand, the somewhat unusual social role of the male carer that has also been recognised in other research (e.g.Ribeiro, Paul & Nogueira, 2007) might contribute to greater social

recognition, appraisal and more offers of help and support. Women, in contrast, conform to social roles and so might receive less practical support from family and friends.

Safety and Security

The importance of a network to fall back on was also linked to elderly spouses' concerns regarding the safety of their partner should the caring spouse be no longer in a position to provide care. Planning for such eventualities, but most importantly the awareness that a network of family and friends would be able and willing to step in, was important for carers' peace of mind. Only one previous report, which explored difficulties of caring in later life was found that also picked up on carers concern about what might happen if they are no longer fit to care (Jopling, 2015, p.8).

In contrast to spouse carers, daughters experienced distinct concerns regarding their parent's physical safety and security. Like husbands, daughters provided care to a parent with advanced dementia living in the community; however, in most cases their care-recipients lived independently. Constant concerns about the care-recipient's safety through wandering behaviour or potential fire or gas-related accidents in the house, impacted on daughters' well-being. These concerns were not lifted until their parent received full-time paid care. In the literature, carers' safety concerns are frequently discussed with respect to technological solutions (e.g. Olsson et al., 2011), but safety concerns do not tend to be discussed in the context of carer well-being. This is also reflected in the absence of safety consideration, or indeed any care-recipient related measures, from the well-being measured reviewed in Chapter 2.

External facilitators to well-being

Among external facilitators to well-being, particularly doctors were identified as of great importance to a spouse's ability to manage their own and their partner's health needs. Husbands overwhelmingly reported receiving great support and recognition from their GPs and other medical professionals. Some wives and daughters, on the other hand, reported struggling with getting their GPs to recognise the impact of dementia on the couple. Rand & Malley (2014, p.379) identified 'difficulties in navigating the system, and experiences of unresponsive or defensive interactions with services' as issues that carers in England experienced, which led to carer frustration and feelings of helplessness. Where health and social service providers accepted carers as partners in the provision of care, this enhanced

carers' well-being and their care experience. A lack of recognition of medical and services needs detracted from their well-being.

Neufeld and colleagues (2007) investigated the experience of non-supportive interactions among female carers. In their sub-samples of women caring for a relative with dementia, women predominantly reported minimisation of their concerns. Perhaps perceived social honour and recognition of men who support their wives with dementia for taking up a traditionally female role (also described in Ribeiro, Paul & Nogueira, 2007) is an underlying reason why more men than women reported support and recognition by health and social services workers.

Despite husbands' active engagement with doctors and charities providing to support the couples, men in this study were reluctant to use home care services. This is consistent with findings from other research (McDonnell & Ryan, 2011; Milligan & Morbey, 2016). While other research suggests a lack of awareness of services available or feelings that others would not provide equally good support, husbands in this study expressed mainly a lack of suitable services and their spouses expressed dislike of receiving support from strangers (Milligan & Morbey, 2016). This suggests perceived differences between support services outside the home that enable the carer to get some time off and home care services invading the couples' private space.

Contrary to spouses, many filial carers sought additional paid support. Nearly all filial carers eventually purchased home care support. While some sons expected home care to provide for all arising care needs, daughters purchased support to fill gaps they could not cover themselves. All daughters remained active in the provision of care when paid community services were purchased. This was only the case for some sons, who also received considerable support from their wives. Daughters' inability to limit or withdraw from the provision of care, the presence of active female support among sons, and spouse carer expectations towards daughters, points towards persistent social expectations towards women to take on care responsibilities in the family.

Sons' abilities to limit their involvement meant that mothers of sons entered institutional care comparatively earlier than parents of adult daughters. It should, however, not be assumed that sons sent their mothers frivolously into care. Their managerial responsibility did not cease following parental admission into institutional care. Regular visits were maintained during which quality of care provided was monitored and substandard practices were pointed out to management (Campbell, 2010). When daughters

decided to move their parents into institutional care, personal and community resources had by then been exhausted. In all interviews with filial carers the message that moving their parent into institutional care improved their well-being dominated.

Health

In the initial definitions of well-being, the concept of physical health prevailed. This is consistent with findings in Chapter 2, where well-being frequently was measured using carers' physical and mental health status. During the interviews, however, it became clear that long-standing health issues or chronic illnesses, as long as they did not cause the carer to be bedbound, were not viewed as detracting from carer ability to look after their relative or indeed their well-being. While reporting a number of illnesses, husbands emphasised that their physical health issues were controlled and did not affect their well-being. Some wives experienced current physical incapacities as detracting from their well-being. Spouse carers concern about what would happen to their partner with dementia, should they themselves experience a health crisis shows the crucial role health plays in people's ability to care.

The experience of mental health issues, on the other hand, were described by carers as having a greater impact on their well-being and ability to care. Some men in this study were found to experience more externalising behaviours, such as being snappy or uptight and experiencing physical pain. Women, on the other hand reported traditional symptoms of exhaustion or feeling anxious and sad. The finding that men and women may experience depression and anxiety differently is consistent with findings by Martin, Neighbors & Griffith (2013). The importance that men and women placed on their mental health in comparison to the other aspects influencing their well-being emphasises the need for available support to carers of people with dementia.

5.4.2 How the conceptual framework of this thesis sits with carers' conceptualisation of well-being

A comparison of the framework presented in this chapter and the framework presented in Chapter 2 shows significant overlap. The relationship between carer and care-recipient appear in both frameworks. Findings presented in this Chapter and the results from Chapter 6 and 7 show that the relationship to the care-recipient is likely to influence patterns of care. Spouse carers and daughters have been found to provide substantial amounts of personal and organisational care as well as supervision, while most sons engage predominantly in organisational tasks.

Care responsibility in the qualitative framework sits well with the circle illustrating 'care-recipient needs' in the conceptual framework. Aspects such as care-recipient depression, anxiety, mood, care needs, behaviour and dependency, but also the time carers spent looking after their relatives, influence the care experience. The qualitative model provided greater insights into how carers conceptualise well-being by explaining not just that the provision of external support through paid and unpaid support as well as service use could influence well-being, but also that the recognition of the carers by doctors and social service workers was an important first step in unlocking resources.

In line with the conceptual framework, the qualitative framework showed that external support has an impact on carer ability to use successful coping mechanisms. The qualitative model further separated support from 'official actors', such as social services providers or charities, and support from family and friends. This distinction was found to be important in the interviews as carers had different expectations from family and friends than from formal services providers, even though both types of actors contributed to carer ability to successfully employ coping mechanisms. Spouses in this study relied predominantly on support from family and friends, some husbands and wives also took up support from charitable organisations offering respite care, joint activity or carer groups. Filial carers, on the other hand relied much more heavily on social services, with their network of family and friends providing some practical but mostly emotional support.

Next, the physical and mental health of carers received distinct mention in the qualitative framework, while in the conceptual framework it was listed as one of many variables influencing well-being. In the interviews, carers emphasised the importance, particularly, of mental health issues stemming from their care responsibilities. This finding reflects well the use of depression and anxiety measures to estimate carer well-being (See Chapter 2).

Safety and security of the care-recipient had not entered the list of variables from the literature out of which the conceptual model was developed. In the interviews, carers stressed the need to know that the care-recipient was physically safe and provided for in case the carer was no longer able to provide care.

Chapter 6

Carer well-being and quality of life over time

This chapter examines whether and how the well-being and quality of life of carers of people with dementia in the community change over time, with particular reference to differences between men and women of different ages. A number of measures capturing well-being and quality of life are analysed using the three datasets START, SHIELD-CSP-RYCT and MODEM. I present statistical models investigating well-being and quality of life for each of the datasets. The results of the different models are then discussed in comparison to each other and in light of the literature.

6.1 Carer well-being and quality of life over time

The analysis in this chapter responds to the research question 'How do well-being and quality of life of male and female carers of people with dementia of different ages change over time?' As outlined in Chapter 2, the well-being and quality of life of family carers of people with dementia can be framed in different ways and is potentially influenced by numerous factors. Owing to this complexity, well-being was analysed using a number of different outcome measures available in MODEM, START and SHIELD-CSP-RYCT (see Chapter 3.5.1). Carer health-related quality of life, on the other hand, was measured in all three datasets through the EQ-5D.

Particular attention is paid to how the variables carer age and gender influenced carer well-being and quality of life. The three datasets START, SHIELD-CSP-RYCT and MODEM offered an unusual possibility of comparing well-being and quality of life of unpaid carers supporting people with dementia in the community over time. Independent variables explored as part of this analysis and described in greater detail in Chapter 3.5.1, were based on the theoretical framework developed in Chapter 2.5, but are limited to some extent by the availability of data collected in the different datasets.

In the literature it has been recognised that carer measures of well-being and quality of life differ between carers who look after a relative with dementia in the community and those who support someone in institutional settings (Pot, Deeg & Van Dyck, 1997; Borsje et al., 2016; Bleijlevens et al., 2015). The analysis in this chapter will therefore focus on carers providing care in the community.

6.2 Descriptive analysis

6.2.1 Descriptive analysis of carer and care-recipient characteristics

The analysis presented in this chapter focuses, as that of Chapter 7, only on unpaid carers supporting people with dementia living in the community. Carer mean age in START (59.9 years) was lower than that of carers in SHIELD-CSP-RYCT (67.3) and MODEM (70.4) (see Table 6.2.1). The proportions of male and female carers in all three studies were comparable; over 65% of carers were women. Greater variation was found in the relationship between carer and care-recipient. In START, the proportions of spouse and filial carers were much more similar (42.5% and 47.5%, respectively), than in the other studies. In both MODEM and SHIELD-CSP-RYCT, the proportion of spouse carers was more than twice that of filial carers (see Table 6.2.2). The proportion of other unpaid carers made up a much smaller proportion; however, their share in START (9.9%) was nearly twice that in SHIELD-CSP-RYCT (5.9%) or MODEM (4.1%). Consistent with the somewhat different demographics, 36.8% of carers in START lived independently of their care-recipient, while over 80% of carers in both SHIELD-CSP-RYCT and MODEM lived together with their care-recipient.

Care-recipient characteristics, on the other hand, did not show greatly different patterns. Mean age of people with dementia in the datasets ranged from 78.9 in START to 79.3 in MODEM. Gender proportions were also more comparable. In START and SHIELD-CSP-RYCT fewer than half the people with dementia in the samples were male, while in MODEM men made up 54.1%. The distribution of dementia severity reflected the different recruitment strategies pursued in each of the studies (Comas-Herrera et al., 2017; Charlesworth et al., 2011; Livingston et al., 2014a). In START (16.7%) and SHIELD-CSP-RYCT (10.9%) carers of people with very mild dementia were recruited. In MODEM participants were grouped into people with mild, moderate and severe dementia. No distinction was made between mild and very mild dementia. The proportion of carers supporting people with mild dementia was roughly even across the datasets, representing between 49.5% (MODEM) and 53.8% (START) of carers. A greater proportion of carers in MODEM supported people with moderate (33.5%) and severe (17.0%) dementia. This was due to a sampling strategy that emphasised the recruitment of roughly even numbers of people with mild, moderate and severe dementia. In START and SHIELD-CSP-RYCT, the proportion of carers supporting a relative with severe dementia in the community was much

lower. About one quarter of the SHIELD-CSP-RYCT sample looked after people with moderate dementia and just below 10% of carers care for people with severe dementia. In START, these were 28.8 % and 0.8% of carers, respectively. For this reason the two categories 'moderate' and 'severe' dementia were collapsed into one category in all three datasets for further analysis.

Table 6.2.1 Descriptive analysis of carer and care-recipient characteristics

	Observations	Mean	Std. Dev.	Min	Max
Carer age					
START	241	59.9	14.2	18	89
SHIELD-CSP-RYCT	255	67.3	11.7	21	91
MODEM	195	70.4	11.7	33	92
Age care-recipient					
START	242	78.9	8.9	53	96
SHIELD-CSP-RYCT	250	79.1	7.9	53	96
MODEM	196	79.3	7.9	54	96

Table 6.2.2 Descriptive analysis of carer and care-recipient characteristics

	START	SHIELD-CSP-RYCT	MODEM
Carer gender			
Male	75 (30.9%)	82 (32.2%)	67 (34.2%)
Female	167 (69.0%)	173 (67.8%)	129 (65.8%)
Relationship with care-recipient			
Spouse	103 (42.6%)	168 (65.9%)	151 (77.0%)
Filial carer .(daughter/ son-in-law)	115 (47.5%)	72 (28.2%)	37 (18.9%)
Other	24 (9.9%)	15 (5.9%)	8 (4.1%)
Co-residence with care-recipient			
No	89 (36.8%)	49 (19.2%)	27 (13.8%)
Yes	153 (63.2%)	206 (80.8%)	169 (86.2%)
Gender care-recipient			
Male	100 (41.3%)	119 (47.2%)	106 (54.1%)
Female	142 (58.7%)	133 (52.8%)	90 (45.9%)
Severity			
Very mild	40 (16.7%)	27 (10.9%)	
Mild	129 (53.8%)	132 (53.4%)	96 (49.5%)
Moderate	69 (28.8%)	64 (25.9%)	65 (33.5%)
Severe	2 (0.8%)	24 (9.7%)	33 (17.0%)

6.2.2 Descriptive analysis of outcome variables

This chapter examines whether and how the well-being and quality of life of carers of people with dementia in the community change over time, with particular reference to differences between men and women of different ages. The reasons for selecting the outcome variables used to measure carer well-being and quality are outlined in Chapter 3.5.1. Health-related quality of life, measured by EQ-5D in both START and SHIELD-CSP-RYCT, showed comparable mean values (0.8) at baseline (see Table 6.2.3). At follow-up, carers in both studies on average experienced a decline in their quality of life. In START, however, no statistically significant difference could be identified (t-test p=0.2) between the EQ-5D mean at baseline and follow-up or between baseline and imputed follow-up scores (p=0.05). Carers in SHIELD-CSP-RYCT, on the other hand, experienced on average a statistically significant reduction in EQ-5D scores between baseline and follow-up (t-test $p<0.0001$) and between baseline and imputed score (t-test $p<0.0001$). MODEM scores revealed a very different pattern. It appears that carers' mean health-related quality marginally increased over time. The difference, however, was not significant between baseline and follow-up (p=0.09), but approached significance when comparing baseline and imputed scores (p=0.06).

Among the HADS depression scores analysed for START and SHIELD-CSP-RYCT, an increase in means could be observed between baseline and follow-up, and between baseline and imputed scores, indicating an increase in depressive symptoms over time. Comparison of means between baseline and follow-up and baseline and imputed scores, did not show statistically significant differences for carers enrolled in START (baseline and follow-up: p=0.41; baseline and imputed score: p=0.26). The non-significant difference in scores over time observed with START variables might be due to the success of the START intervention, which was found to support carers effectively over time (Livingston et al., 2014a). In SHIELD-CSP-RYCT, differences between means were statistically significant (baseline and follow-up: p=0.004; baseline and imputed score: p=0.004).

Similarly, the mean scores on HSQ question 12, inquiring about carer happiness, suggest a reduction in happiness over time; however, a comparison of means did not show statistically significant differences between baseline and follow-up (p=0.41) or between baseline and imputed scores (p=0.26). The PGI, investigated using SHIELD-CSP-RYCT, also showed a decrease of perceived personal growth between baseline and follow-up. In

this case, the difference in means between baseline and follow-up ($p<0.0001$) and between baseline and imputed scores ($p<0.0001$) were both highly significant. The MODEM GHQ, as with the MODEM EQ-5D scores, showed a reversed trend, indicating slightly better psychological health among carers one year on. This different pattern might be related to the MODEM enrolment mechanism, where substantial numbers of participants were enrolled through memory services following diagnosis. It might be that when carers were initially interviewed, the news of the diagnosis had not yet settled in, whereas one year on carers had adjusted to the situation. However, no statistically significant difference was observed between baseline and follow-up ($p=0.08$) or between baseline and imputed scores ($p=0.70$). As the four personal well-being questions were only introduced at follow-up, there were no baseline scores available for comparison to see whether carer mean ratings of the questions had changed.

Table 6.2.3 Descriptions of outcome variables

	Observations	Mean	Std. Dev.	Min	Max
EQ-5D					
START baseline	242	0.8	0.3	-0.0	1
START follow-up	164	0.8	0.2	-0.18	1
START imputed	241	0.7	0.3	-0.22	1
SHIELD-CSP-RYCT baseline	255	0.8	0.2	-0.18	1
SHIELD-CSP-RYCT follow-up	235	0.7	0.3	-0.59	1
SHIELD-CSP-RYCT imputed	241	0.7	0.3	-0.59	1
MODEM baseline	192	0.7	0.3	0.0000	1
MODEM follow-up	170	0.7	0.3	0.0002	1
MODEM imputed	196	0.7	0.3	-0.02	1.23
HADS Depression					
START baseline	242	5.4	3.8	0	18
START follow-up	187	5.4	4.2	0	21
START imputed	241	5.7	4.3	0	21
SHIELD-CSP-RYCT baseline	255	5.6	4.2	0	21
SHIELD-CSP-RYCT follow-up	238	6.2	4.4	0	21
SHIELD-CSP-RYCT imputed	214	6.2	4.4	0	21
HSQ 12					
START baseline	241	3.0	1.4	1	6
START follow-up	166	3.1	1.3	1	6
START imputed	241	3.2	1.3	1	1
PGI					
SHIELD-CSP-RYCT baseline	255	14.0	3.2	3	18
SHIELD-CSP-RYCT follow-up	236	12.3	2.3	5	18
SHIELD-CSP-RYCT imputed	241	12.3	2.2	5	18
GHQ 12					
MODEM baseline	194	2.6	3.2	0	12
MODEM follow-up	171	2.5	3.3	0	12
MODEM imputed	196	2.5	3.2	-3.07	12.14
PQW questions (1-4)					
MODEM follow-up (PWB 1)	167	6.8	1.9	0	10
MODEM imputed	196	6.8	1.9	-0.01	11.39
MODEM follow-up (PWB 2)	168	7.7	1.9	0	10
MODEM imputed	196	7.7	1.9	-0.09	11.81
MODEM follow-up (PWB 3)	167	6.8	1.9	0	10
MODEM imputed	196	6.8	1.9	-0.01	11.39
MODEM follow-up (PWB 4)	168	3.2	2.9	0	10
MODEM imputed	196	5.1	3.0	-3.33	10.67

6.3 Analysis of START

START data was analysed using three models. One focused on health-related quality of life using the EQ-5D score and two models investigated carer well-being through the proxy measures HADS depression and HSQ question 12 'Have you been a happy person?'
The underlying concepts leading to the choice of outcome variables were outlined in Chapters 2 and 3. As missing data was identified, multiple imputations were performed to improve statistical power of the model (see Chapter 3.5.2). This section shows the complete case analysis of the three models. Next the imputation process is outlined. Finally, analysis using the imputed data for each of the three models is presented.

6.3.1 Complete case analysis

EQ-5D

Initial checks showed that EQ-5D was not quite normally distributed. Tests showed that the distribution of the variable benefited from squaring the values of the outcome measure. Next, univariate regression analyses between the EQ-5D score at 12 months and the identified independent variables were performed (see Appendix 5.3.1). The variables carer age, relationship between carer and care-recipient, carer employment, co-residence with the person with dementia, carer self-rated health, the MCTS score, HADS anxiety and depression as well as the coping mechanisms denial and religious coping were found to be significantly associated with EQ-5D at follow-up. Furthermore, gender of the care-recipient and the experience of challenging behaviour by the person with dementia (measured by NPI) also showed significant associations.

In a next step, as outlined in Chapter 3.5.2, a first model was built exploring the relationship between health-related quality of life and a set of key carer and care-recipient characteristics. The fully detailed model can be found in Appendix 5.3.2. The model showed no statistical significance for carer age or gender. Carer health-related quality of life was only found to be positively associated with the EQ-5D baseline score.

Then the final model was built, exploring the pre-determined carer and care-recipient variables included in the first model and the variables that showed a significant relationship in the univariate analysis. The final model contains 163 observations and has an r^2=0.39. It does not show significant associations for carer age and gender, which means that no difference in the health-related quality of life could be observed between male and female carers or between carers of different ages. Significant positive associations, however, were

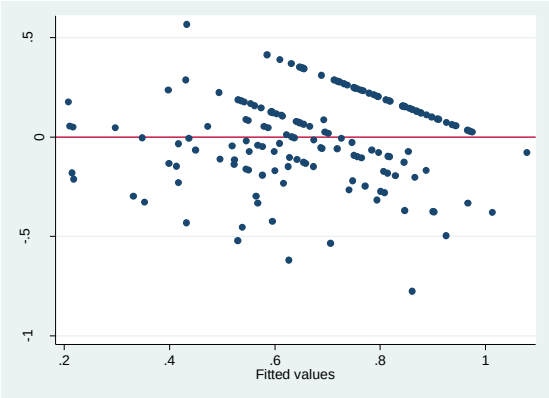
found for unpaid carers who were related to the person with dementia other than being their spouses or filial carers. In addition, carers using religious coping mechanisms were significantly more likely to experience lower health-related quality of life, while those who expressed good quality of life at baseline (as in the first model) were also more likely to experience this 12 months later. Finally, carers whose care-recipient exhibited challenging behaviour were more likely to declare lower health-related quality of life. Residuals of the model, did not give reason for concern (see Box 6.3.1).

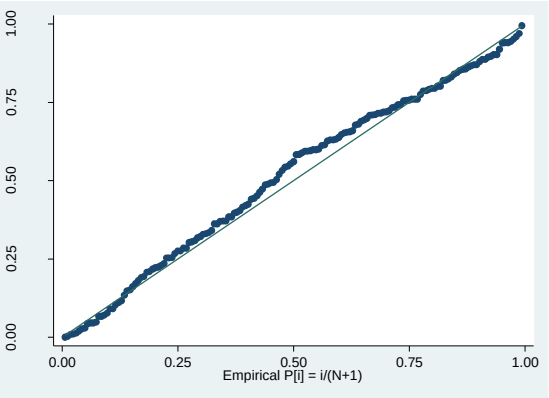
Table 6.3.1 multiple regression analysis for EQ-5D 12 months

EQ-5D 12 months	N= 163	
Independent Variable	Coefficient	95% CI
Carer age	-0.0026	-0.0063; 0.0011
Gender		
Female	-0.0319	-0.1123; 0.0484
Relationship		
Child/-in law	0.0837	-0.0175; 0.1849
Other	0.1773**	0.0311; 0.3235
COPE religious coping	-0.0195**	-0.0379; -0.0012
EQ-5D baseline	0.4079***	0.2699; 0.5461
Dementia severity		
Mild	0.0018	-0.1002; 0.1038
Moderate & severe	-0.0493	-0.1629; 0.0644
NPI	-0.0028**	-0.0049; -0.0007
Randomization		
Intervention	0.0339	-0.0446; 0.1126
Constant	0.6229***	0.3032; 0.9428

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.3.1 Residuals of multiple regression analysis for EQ-5D (12 months)





HADS Depression

As before, the distribution of the outcome variable was reviewed and improved through a square-root transformation. Both the univariate and the multiple regression analyses were performed using the transformed HADS depression score.

The univariate regression analysis found statistically significant associations with 18 of the tested independent variables; these include: carer age and gender, relationship to the care-recipient, co-residence, self-rated carer health, the HADS anxiety measure, the MCTS, the Zarit burden inventory, the presence of other unpaid carers and a few sub-categories of the COPE inventory (denial, self-distraction, behavioural disengagement, venting, humour and self-blame). Additionally, three variables related to the care-recipient showed a significant association, including age of the care-recipient, dementia severity and the NPI inventory.

A first model exploring a predetermined set of carer and care-recipient variables did not find a statistically significant relationship between the HADS depression score and carer age and gender. HADS depression score at follow-up, however, showed a statistically significant relationship with the variables age of the care-recipient, moderate and severe dementia, the HADS depression baseline score and participants enrolled in the intervention groups.

Next, the final multiple regression model was built. The pre-determined carer and care-recipient characteristics as well as the significant variables from the univariate analysis

were introduced to the regression model in a stepwise fashion. Only variables improving the model, as indicated by the AIC, were included in the model (see Chapter 3.5.3).

In the final model, the variables carer age and gender were not found to be statistically significant associated with the HADS depression score at 12 months. Instead, carers related to people with dementia other than being their spouse of filial carer were found to have a greater likelihood of experiencing fewer symptoms of depression than spouses.

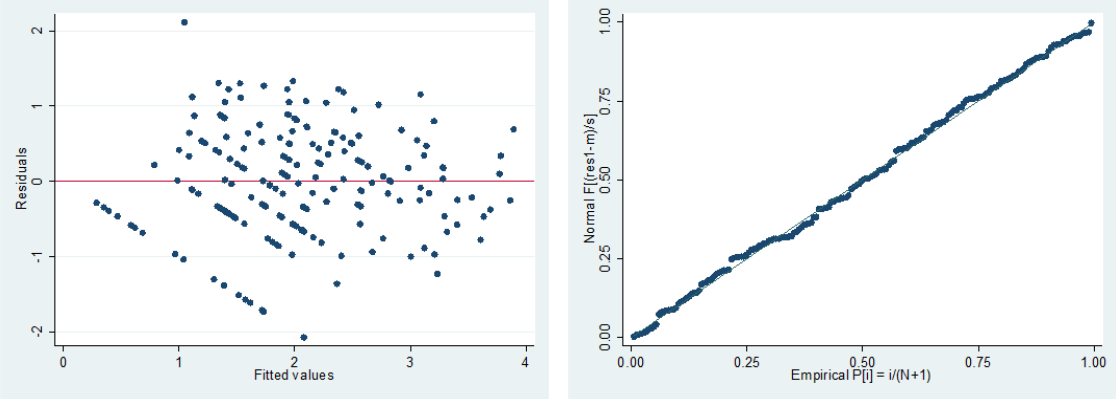
Carers whose care-recipient had moderate or severe dementia were more likely to experience more depression symptoms at 12 months than those whose care-recipient had very mild dementia at baseline. Carers who declared using denial as a coping mechanism at the beginning of the study were found to be more likely to experience more depressive symptoms at follow-up. Likewise, carers who reported higher depression scores at baseline were significantly more likely to experience more depressive symptoms at follow-up. Consistent with analysis of the trial data elsewhere, carers who participated in the START intervention at baseline were significantly more likely to exhibit lower depression scores at follow-up than those who did not participate in the intervention (Livingston et al., 2014a). Residuals of the model did not indicate problems with the assumption of an existing linear relationship or problems with variance of the error term.

Table 6.3.2 multiple regression analysis for HADS depression 12 months

HADS depression 12 months	N= 185	
Independent Variable	Coefficient	95% CI
Carer age	0.0108	-0.0024; 0.0241
Gender		
Female	0.1317	-0.1109; 0.3743
Relationship		
Child/-in law	-0.0735	-0.4929; 0.3460
Other	-0.6517**	-1.1376; -0.1658
Dementia severity		
Mild	0.2039	-0.1051; 0.5129
Moderate & severe	0.3907**	0.0377; 0.7438
COPE denial	0.1209**	0.0017; 0.2401
Zarit	0.0076*	-0.0007; 0.0159
HADS depression baseline	0.1331***	0.0926; 0.1737
Carer self-rated health		
Good to excellent	-0.1720	-0.4539; 0.1098
Age care-recipient	-0.0147*	-0.0313; 0.0197
Randomization		
Intervention	-0.2545**	-0.4923; -0.0167
Constant	1.6105**	0.4239; 2.7970

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.3.2 Residuals of multiple regression analysis for HADS depression (12 months)



HSQ Question 12

Initial checks of the distribution of HSQ 12 suggested that the variable would best be analysed without any transformation. As with the other outcome variables, univariate regression analyses revealed a number of associations when investigating 'happiness'. The HSQ question 'Have you been a happy person?' was found to be significantly associated with the variables carer gender, carer self-rated health, the MCTS, the Zarit burden inventory, the HADS depression and anxiety measure as well as the COPE sub-categories self-distraction, venting, and self-blame. In addition, caring for a person with moderate dementia and hospitalisation of the person with dementia showed significant associations with HSQ question 12 at follow-up. The tables illustrating results of the analyses can be found in Appendix 5.3.1. The first model exploring the relationship between the HSQ 12 question on happiness and carer and care-recipient characteristics only found a statistically significant relationship with the HSQ 12 baseline score (see Appendix 5.3.2).

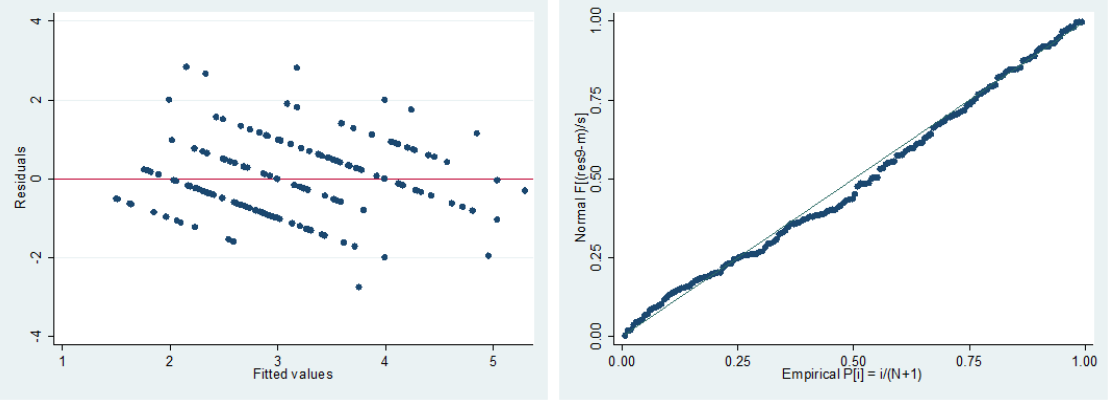
The second model, built using a stepwise approach described in Chapter 3.5.2, contained 165 observations (r^2=0.43). The model did not find statistically significant associations with carer age and gender. This suggests that there was no difference in how male and female carers rated their happiness or in the experience of carers of different ages. However, other significant associations were found. Carers who had higher depression scores at baseline were found to be less likely to express being a happy person at follow-up. Similarly, carers who used venting as a coping mechanism at baseline were also less likely to express happiness one year on. This was also true for those who had rated their happiness at baseline as low. Residuals of this model did not suggest any concerns about the model (see Box 6.3.3)

Table 6.3.3 multiple regression analysis for HSQ-12 12 months

HSQ12 12 months	N= 165	
	Coefficient	95%CI
Carer gender		
Female	0.0515	-0.2979; 0.4011
Carer age	0.0008	-0.0114; 0.0129
Carer self health		
Good to excellent	-0.3764*	-0.7898; 0.0369
HADS depression	0.0709**	0.0169; 0.1251
COPE venting	0.1231**	0.0085; 0.2377
HSQ 12 baseline	0.3323***	0.1858; 0.4788
Dementia severity		
Mild	-0.0558	-0.4840; 0.3724
Moderate	0.2123	-0.2696; 0.6943
Hospitalisation care-recipient	0.2759	-0.0905; 0.6423
Randomisation		
Intervention	-0.2295	-0.5637; 0.1048
Constant	1.5302**	0.4281; 2.6322

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.3.3 Residuals of multiple regression analysis for HSQ 12 (12 months)



6.3.2 Imputation

As pointed out above and illustrated in Table 6.3.4, a number of variables relevant to the analysis of this dataset had missing observations at baseline and/or follow-up. As outlined in Chapter 3.5.2, imputation is often used as a mechanism to overcome missing data by calculating likely estimates of the missing values. For the variables missing in the START dataset an MAR assumptions can be made (Graham, 2009).

In this analysis, the outcome variables HSQ12, EQ-5D and HADS depression at 12-month follow-up had between 23% and 32% missing values. There is some debate in the literature as to whether it is better to impute summary scale scores or to impute each item. Graham (2009) suggests that at least half of items should be available so that scale scores can be imputed appropriately. Furthermore, the items should have high coefficient alphas and similar item-total correlations (Azur et al., 2011, p.45). As these assumptions held true for the HADS depression score, the summary scale was imputed. For EQ-5D, no item scores were available in the dataset, which meant that the scale had to be imputed. HSQ12 question 12 represented only one item of the HSQ12 scale.

Furthermore, the independent variable measuring whether other carers were present to support the unpaid carer interviewed for this study, the NPI baseline score and the carers educational qualifications showed missing data (see Table 6.3.4). As multiple imputations tend to be improved by the inclusion of relevant variables that are not the direct interest of the analysis I included the variables for costs at 12 months and MCTS at 12 months (Collins, Schafer & Kam, 2001; Schafer, 2003). Both auxiliary variables were correlated with the outcome variables (von Hippel, 2007). There was limited choice of variables in the START dataset that were not used for the analysis in this chapter. Therefore, auxiliary variables including missing variables were chosen.

The variables were imputed using chained equations. This means that for each variable registered for imputation a series of regression models were run, taking into account the other variables registered as well as independent variables predictive of missing values and variables relevant to the subsequent analysis (Azur et al., 2011). In this case, the additional, independent baseline variables were co-residence with the care-recipient, relationship to the carer, EQ-5D, HADS depression, carer age, care-recipient age, carer gender and carer allocation to intervention or control group. I used logistic regression analysis to examine which variables predicted missingness (Spratt et al., 2010).

Continuous variables were imputed using ordinary least squares regression equations, where necessary. Truncation was used to limit the imputed values to range between minimum and maximum values of the measures. The maximum value an EQ-5D score can take, for instance, is one. Binary variables were imputed using logistic regression equations and for ordinal variable ordered logistic regression analysis was used. A total of 20 imputations were computed as missing data among variables of interest ranged from 23% to 32%, as it is recommended that the number of imputations should be similar to the proportion of missing data (Graham, Olchowski & Gilreath, 2007; Spratt et al., 2010; White, Royston, & Wood, 2011; Royston & White, 2011).

Table 6.3.4: Imputation of START data

Variable	Complete	Incomplete	Imputed	Total
MCTS 12 months	162	80	79	242
M12Cost	187	55	54	242
HSQ score 12 months	166	76	75	242
HSQ question 12 12 months	166	78	75	242
EQ-5D 12 months	164	78	77	242
HADS depression 12 months	187	55	54	242
Other carers	220	22	21	242
NPI baseline	241	1	1	242
Carer education	206	36	36	242

Following the imputation process, summary statistics for the observed and imputed values were compared to see whether any of the imputed variables showed impossible values. Next, the Monte Carlo error to assess variability of 'standard deviations across repeated runs of the same imputation procedure' was investigated (White, Royston & Wood, 2011, p.387). This step provides confidence that repeat analysis of the data would lead to similar results. According to White, Royston & Wood (2011, p.388) the Monte Carlo error of a coefficient is supposed to be 'approximately ten per cent of its standard error', the Monte Carlo error of the test statistic […] is approximately 0.1', and 'the Monte Carlo error of the P-value is approximately 0.01 when met these criteria.

Finally, the imputed data could be analysed. Following the recommended approach in the literature (Azur et al., 2011; von Hippel, 2007; White, Royston & Wood, 2011), the regression models using a stepwise approach were conducted using only one of the imputed datasets. Then, the three best models identified in the analysed imputed dataset were tested for at least three other imputed datasets. If the Akaike criterion identified the same very

best model in all imputed datasets tested, this regression model was analysed using a combined approach including estimates from all imputed datasets. Where the Akaike criterion did not uniformly identify the same very best model, each of the datasets was explored in greater detail until a model was identified that proved to be the very best model in the majority of datasets.

6.3.3 START analysis using imputed data

EQ-5D

Univariate analysis with the independent variables was also conducted for the imputed EQ-5D 12-month score. As in the complete case analysis, the EQ-5D was analysed using a square transformation. Significant associations were found for carer age, employment, relationship to the care-recipient, co-residence with the care-recipient, carer self-rated health, both HADS anxiety and depression scores, the COPE sub-categories denial, behavioural disengagement, venting and religious coping, the presence of other unpaid carers as well as scores of the Zarit- and MCTS- scales. In addition, the NPI score also showed statistically significant associations with the EQ-5D follow-up score. An overview can be found in the Appendix (Table 5.3.3).

A first model investigating the relationship between health-related quality of life and carer and care-recipient characteristics was also performed for the imputed data (see Appendix 5.3.4). As with the complete case analysis, a significant association could only be found between EQ-5D baseline and follow-up scores.

The final model, established after stepwise exploration of carer and care-recipient characteristics and the significant variables from the univariate analysis, included 241 observations based on 20 imputations. The model revealed a statistically significant relationship between carer age and health-related quality of life at follow-up. This indicates that younger carers were more likely than older carers to rate their health-related quality of life higher one year after onset of the trial. No significant association was found for carer gender.

In addition, two more variables in the model showed statistically significant associations with the outcome measure. Firstly, the EQ-5D baseline measure was positively associated with the 12-month measure. This means that carers who declared good health-related quality of life at the beginning of the trial were also more likely to experience good quality of life one year on. Secondly, where people with dementia exhibited challenging

behaviour at baseline, unpaid carers were more likely to rate their health-related quality of life lower at follow-up. Comparison of residuals between non-imputed data and the randomly selected imputations four and 15 displayed here showed that imputation did not affect residuals substantially (see Box 6.3.5).

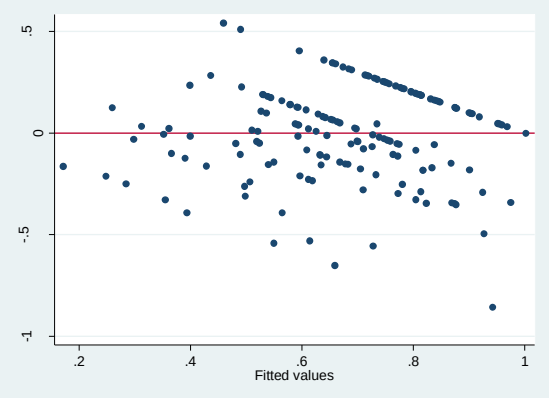
Table 6.3.5 multiple regression analysis for EQ-5D 12 months

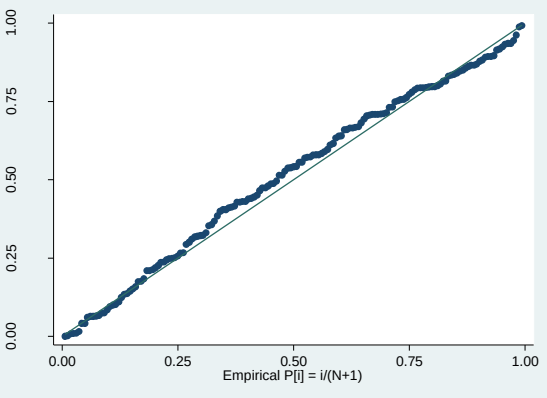
EQ-5D 12 months	N= 241; Imputations=20	
	Coefficient	95%CI
Carer gender		
Female	-0.0221	-0.1139; 0.0696
Carer age	-0.0040**	-0.0074; -0.0015
COPE denial	-0.0240	-0.0634; 0.0154
EQ-5D baseline	0.4272***	0.2861; 0.5684
NPI	-0.0031**	-0.0052; -0.0009
Severity		
Mild	-0.0226	-0.1252; 0.0799
Moderate & severe	-0.0551	-0.1638; 0.0536
Randomisation		
Intervention	0.0303	-0.0563; 0.1169
Constant	0.5711***	0.4409; 0.9811

*p≤0.10 **p≤0.05 ***p≤0.01

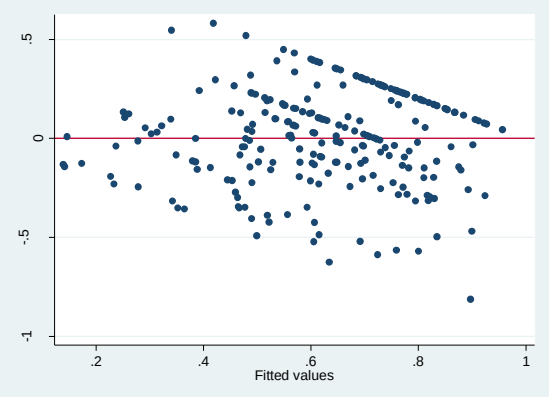
Box 6.3.5 Overview residuals

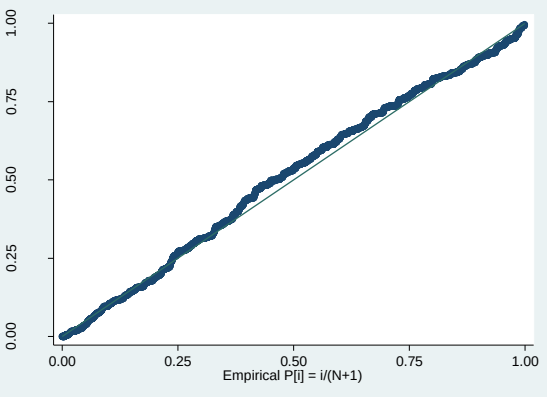
Imputation 0



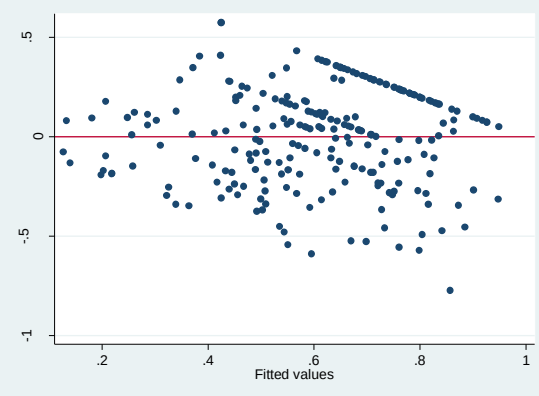


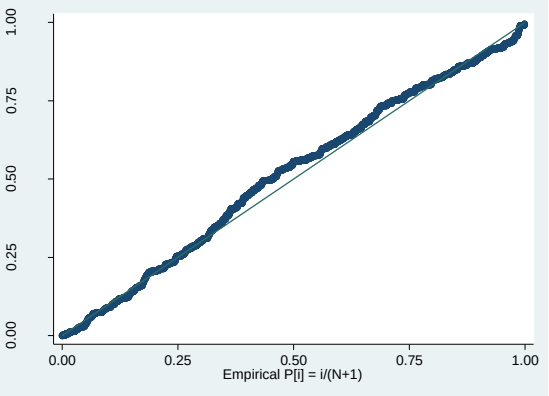
Imputation 4





Imputation 15





HADS Depression

Following the imputation of the dataset univariate regression analysis was conducted between the HADS 12-month depression score and the independent variables as previously done for the complete case analysis. The normality assumption of the outcome variable was improved through a square-root transformation. An overview can be found in Appendix 5.3.3. Significant associations were identified between the HADS follow-up score and carer gender, the relationship to the care-recipient, co-residence with the care-recipient, the presence of other carers, HADS anxiety at baseline, six sub-categories of the Cope measure (denial, self-distraction, behavioural disengagement, venting, humour and self-blame) as well as the Zarit and MCTS baseline scores. In addition, some variables focusing on the care-recipient showed statistical significance. These were age and gender of the care-recipient, dementia severity and the QoL-Ad and NPI baseline scores. A first multiple regression model exploring the relationship between HADS depression and follow-up and the set of pre-determined carer and care-recipient characteristics showed similar results as found with the complete case analysis model. Associations were found with dementia severity (moderate & severe), the HADS baseline score and enrolment in the intervention group (see Appendix 5.3.4).

The final imputed model, built using the stepwise approach outlined in Chapter 3.5.2, included 235 observations and was based on 20 imputations. No statistically significant association could be observed between HADS depression at follow-up and carer age or gender. Instead, significant associations were found for the variables: other carers, HADS depression at baseline, using denial as a coping mechanism, care-recipient age, caring for a person with moderate dementia and being enrolled in the START intervention. The negative association between the presence of other carers and the outcome measure suggests that in a care situation, where more than one unpaid carer contributed to supporting a person with dementia at baseline, the depression score of the main carer at follow-up was better compared to those carers carrying the care responsibility single-handedly. Similarly, carers who were enrolled in the START intervention and those who cared for older people with dementia were more likely to indicate fewer depressive symptoms at follow-up. On the other hand, carers who rated their depression scores higher at baseline were more likely to experience more depressive symptoms 12 months later. Similarly, carers' who used denial as a coping mechanism at baseline were also more likely

to live with more depressive symptoms one year later. Residuals, as displayed in Box 6.3.6, were not found to vary considerably between imputations.

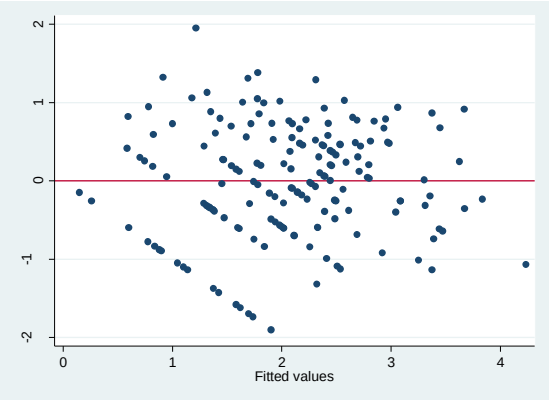
Table 6.3.6 multiple regression analysis for HADS depression 12 months

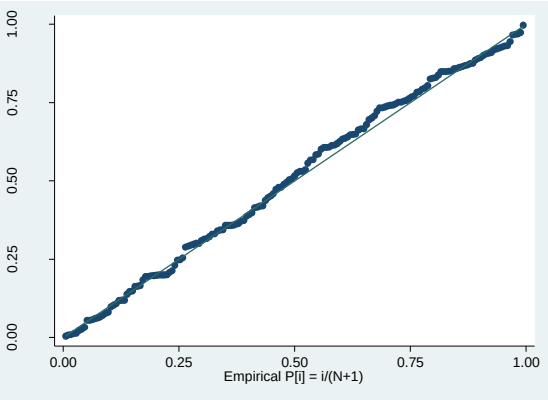
HADS depression 12 months	N= 235; Imputations=20	
	Coefficient	95%CI
Carer gender		
Female	0.0754	-0.1569; 0.3077
Carer age	0.0084*	-0.0008; 0.176
Other carers		
Yes	-0.2989**	-0.5372; -0.0607
Carer self-rated health		
Good to excellent	-0.1883	-0.4553; 0.0786
HADS depression baseline	0.5137***	0.3713; 0.6563
COPE denial	0.1242**	0.0095; 0.2389
Zarit burden	0.0059	-0.0021; 0.0140
Age care-recipient	-0.0127**	-0.0247; -0.0007
Dementia severity		
Mild	0.2305	-0.0626; 0.5237
Moderate	0.3643**	0.0323; 0.6963
Randomisation		
Intervention	-0.2868**	-0.5122; -0.0615
Constant	1.4169**	0.2185; 2.6155

*p≤0.10 **p≤0.05 ***p≤0.01

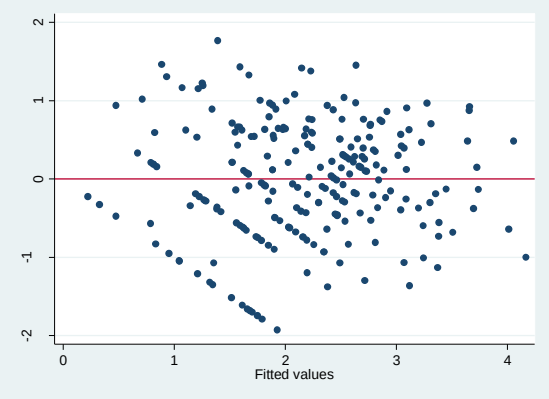
Box 6.3.6 Overview residuals

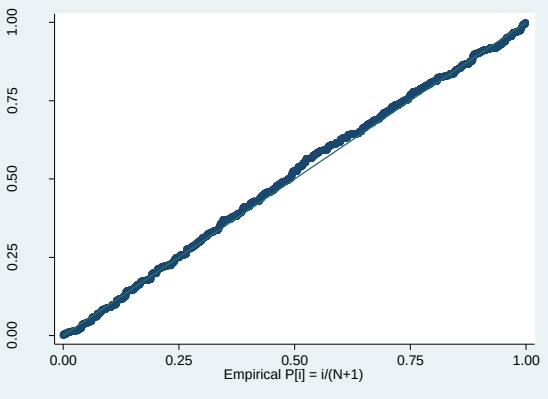
Imputation 0



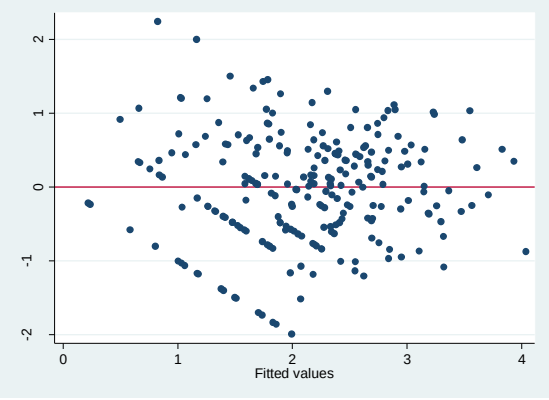


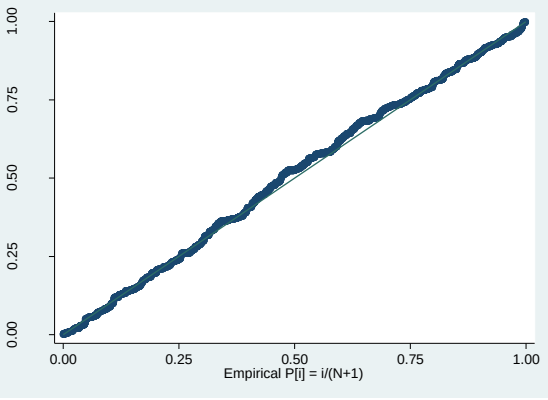
Imputation 4





Imputation 15





HSQ Q12

Analysis performed for HSQ question 12 ‘Have you been a happy person?’ as part of the complete case analysis was also repeated following imputation of the data. Significant associations from the univariate regression analysis were found for carer gender, co-residence with the person with dementia, carer self-rated health, HADS depression and anxiety scores, the COPE sub-categories self-distraction, behavioural disengagement, venting and self-blame, and for the ZARIT and MCTS baseline scores. Dementia severity and challenging behaviour exhibited by the care-recipient (NPI) also showed significant associations with HSQ question 12 at follow-up. The variable was best analysed without any transformation. The full details can be found in Appendix 5.3.3. The first multiple regression model focusing on carer and care-recipient characteristics only found an association between the HSQ question 12 baseline and follow-up measure (see Appendix 5.3.4).

Consistent with the other models run for this analysis, the model for HSQ question 12 was started using the variables carer age and gender and the HSQ question 12 baseline score and the dummy variable indicating allocation to intervention or control arm of the study. The imputed model included 236 observations and was based on 20 imputations. Neither carer age nor carer gender were found to be significantly related to carer happiness at follow-up.

The model, however, showed significant associations between carer happiness and the HADS depression score at baseline as well as for carers’ baseline happiness rating. The positive association with the HADS depression score indicates that carers who had low depression scores at baseline were more likely to express greater happiness one year on. The same mechanism appears to operate with carers who stated having been happy at baseline. They had greater chances of also declaring to be happy at follow-up. Residuals of the model did not give reason for concern (see Box 6.3.7).

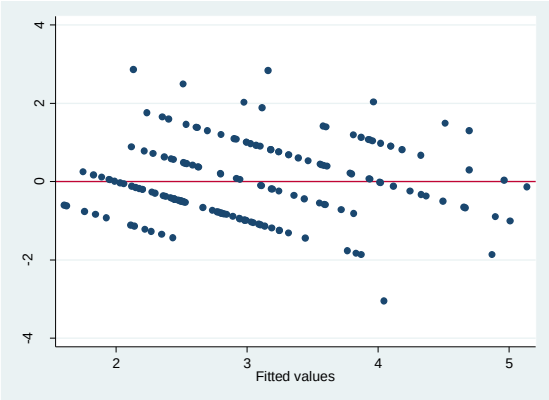
Table 6.3.7 multiple regression analysis for HSQ question 12 months

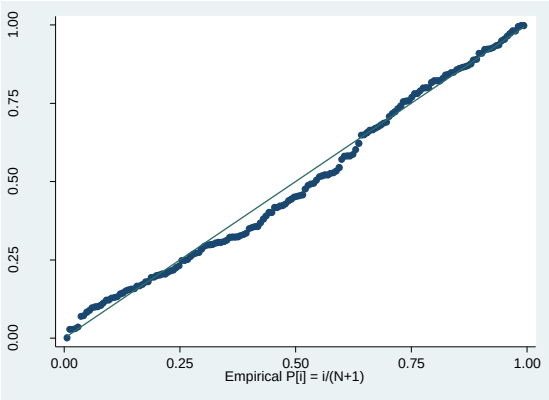
HSQ 12 12 months	N= 236; Imputations=20	
	Coefficient	95%CI
Carer gender		
Female	0.1168	-0.2295; 0.4631
Carer age	0.0005	-0.0110; 0.0119
Carer self-rated health		
Good to excellent	-0.3102	-0.6954; 0.0749
HSQ 12 baseline	0.2409**	0.1045; 0.3773
HADS depression	0.0931**	0.0402; 0.1459
Severity		
Mild	0.0256	-0.4089; 0.4600
Moderate	0.2005	-0.2761; 0.6769
Randomisation		
Intervention	-0.2017	-0.5503; 0.1469
Constant	1.1642	-0.001; 2.9284

*p≤0.10 **p≤0.05 ***p≤0.01

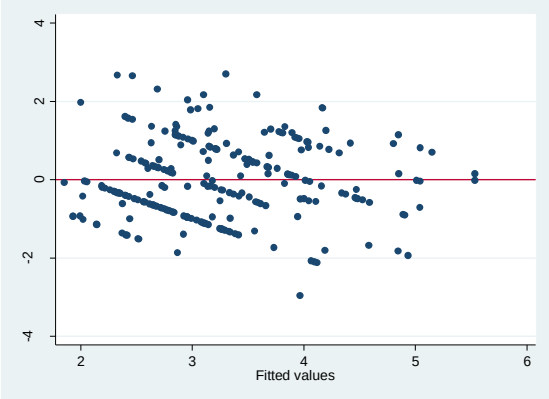
Box 6.3.7 Overview residuals

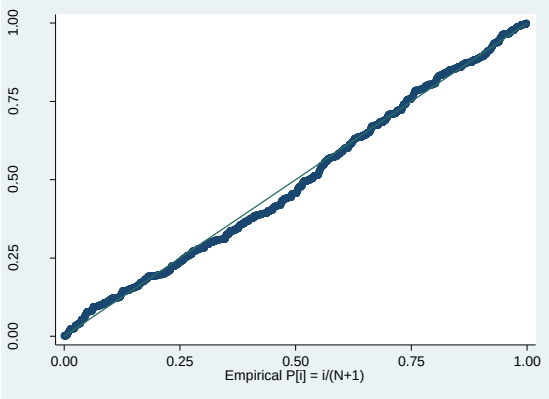
Imputation 0



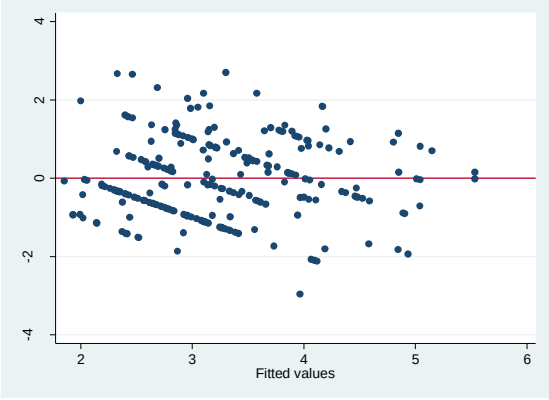


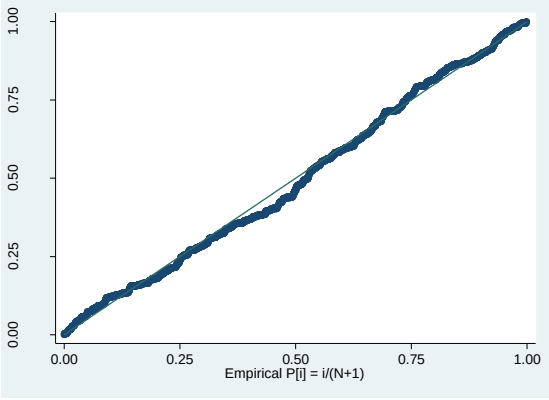
Imputation 4





Imputation 15





6.4 Analysis of SHIELD-CSP-RYCT

Missing data in the dataset SHIELD-CSP-RYCT was imputed by Zoë Hoare and Juanita Hoe as part of the initial analysis of the SHIELD-CSP-RYCT for the main study (conducted prior to this thesis study). Detailed information on imputation procedures can be found elsewhere (Charlesworth et al., 2016). Since the study interest in the initial analysis of SHIELD-CSP-RYCT is related to the aim of this thesis it was decided that the imputed dataset could be used for this analysis.

As in the analysis of START data, univariate regression models using the imputed data of the independent variables were run for three outcome scores: the EQ-5D, the PGI and the HADS depression score at 12 months. This helped to establish initial associations, which then informed which variables to include for the multiple regression analyses. Furthermore, as in the START analysis, for each outcome measure a first multiple regression model exploring the relationships between the outcome measure and a set of carer and care-recipient characteristics were explored (see Chapter 3.5.2 for details of the approach to the data analysis).

6.4.1 SHIELD-CSP-RYCT analysis using imputed data

<u>The EQ-5D score</u>

Prior to the analysis, the distribution of the outcome variable was tested for normality. The EQ-5D outcome variable was found to benefit from a squared transformation. Next, univariate regression analyses between EQ-5D scores at 12-months follow-up and the independent variables at baseline showed associations for a number of variables, namely carer gender, relationship to the care-recipient, carer education, carer employment, co-residence with the person with dementia, the three scores of the RSSE questionnaire indicating different aspects of care management (obtaining respite, responding to disruptive patient behaviour and controlling upsetting thoughts), the HADS scores for anxiety and depression, both physical and mental health components of the SF-12, the presence of other unpaid carers and the loneliness score used in this study. With respect to care-recipient variables, significant associations were found for gender of the person with dementia, dementia severity, the ADCS score measuring limitations in activities of daily living and instrumental activities of daily living, the NPI score measuring challenging behaviour, and several coping mechanisms identified through the COPE measure (denial, behavioural disengagement, venting and self-blame) (see Appendix 5.4.1).

The first model showed a significant association between EQ-5D at follow-up and being a female carer, the EQ-5D baseline score and supporting a person with mild dementia (see Appendix 5.4.2). The final model included 241 observations based on five imputations and also found a significant association with carer gender. This result suggested that female carers were more likely to experience lower health-related quality of life than their male counterparts. No statistically significant association was found for carer age.

Five other variables were also found to be significantly associated with the 12-month EQ-5D score. First, the EQ-5D baseline score indicated that carers who experience greater quality of life at the beginning of the study were also more likely to have better quality of life one year on. Similarly, filial carers in comparison to spouse carers were more likely to express higher quality of life at follow-up. Carers of people with mild dementia, in comparison to carers of people with very mild dementia, were more likely to experience lower health-related quality of life. Furthermore, unpaid carers who used the coping mechanisms self-blame or behavioural disengagement were also less likely to rate highly on the EQ-5D measure at follow-up. Attempts to improve the distribution of residuals through further transformation of the outcome variable did not show improvements (see Box 6.4.1).

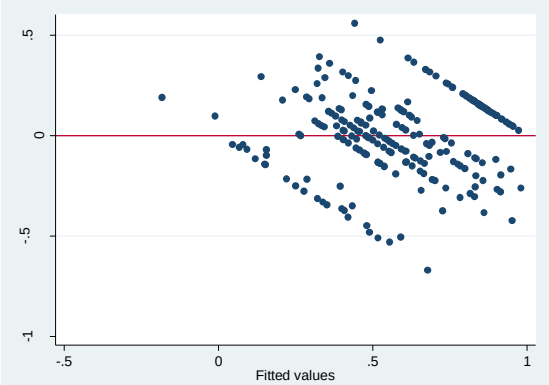
Table 6.4.1 multiple regression EQ-5D 12-month score

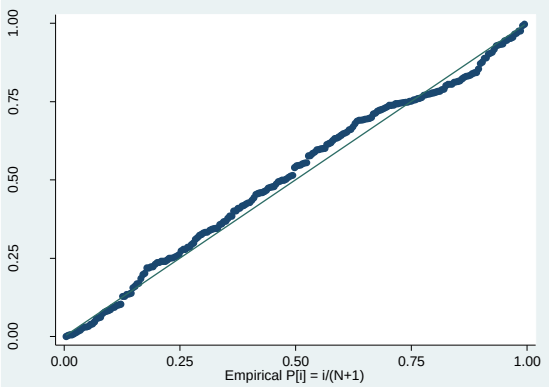
EQ-5D 12 months	N=241; Imputations=5	
	Coefficient	95%CI
Carer gender		
Female	-0.0682**	-0.1287; -0.0075
Carer age	0.0017	-0.0019; 0.0054
Relationship		
Child	0.1404**	0.0533; 0.2275
Other	0.0493	-0.0772; 0.1758
COPE self-blame	-0.0288**	-0.0538; -0.0039
COPE behavioural disengagement	-0.0480**	-0.0816; -0.0144
COPE venting	0.0154	-0.0057; 0.0365
EQ5D baseline	0.6792***	0.5716; 0.7867
Dementia severity		
Mild	-0.1201**	-0.2108; -0.0294
Moderate	-0.0408	-0.1415; 0.0600
Severe	-0.1165*	-0.2361; 0.0031
Randomisation		
Only CSP	0.0615	-0.0365; 0.1596
Only RYCT	-0.0138	-0.0993; 0.0716
SHIELD & CSP	-0.0041	-0.0988; 0.0816
Constant	0.2606	-0.0926; 0.6138

*p≤0.10 **p≤0.05 ***p≤0.01

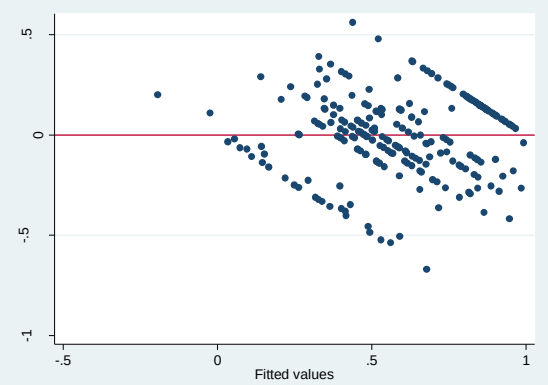
Box 6.4.1 Overview residuals

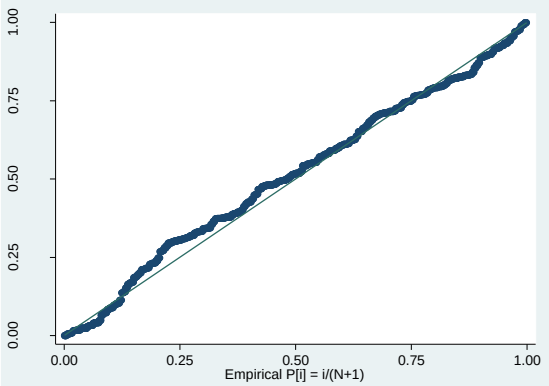
Imputation 0



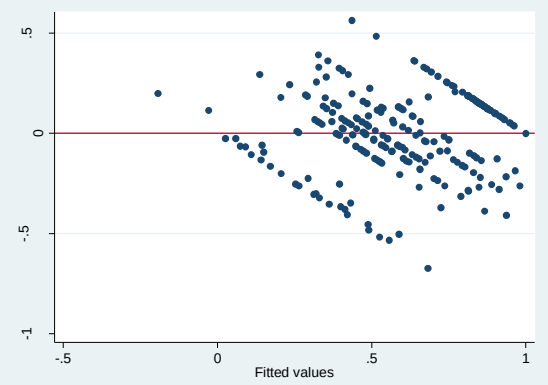


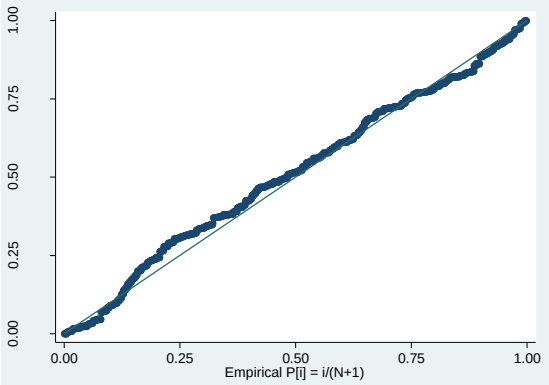
Imputation 1





Imputation 4





The HADS depression score

The second outcome variable investigated with SHIELD-CSP-RYCT data as a proxy measure for carer well-being is the HADS depression score. The normality assumption was improved through a square-root transformation. As above, a selection of relevant variables was investigated through univariate analysis. The HADS depression score was found to be associated with the relationship between carer and care-recipient (adult-child), a measure of the quality of relationship between carer and care-recipient (CQCPR score), co-residence, time the co-resident can be left alone (12 to less than 18 hours), the three RSSE categories 'obtaining respite', 'responding to disruptive patient behaviours', 'controlling upsetting thoughts', the physical and mental health components of the SF-12, loneliness, quality of life of the care-recipient as rated the by the carer, ADL and IADL needs, a rating of challenging behaviour by the care-recipient (NPI), and a number of COPE sub-categories (denial, substance use, emotional support, behavioural disengagement, venting and self-blame). The full table can be found in Appendix 5.4.1.

Analysis of the HADS depression score at 12-months follow-up included 237 observations based on five imputations. Carer age was negatively associated with carer depression scores at 12-months. This means that younger carers were more likely to experience more symptoms of depression and older carers were more likely to experience good mental health at follow-up. No significant association for carer gender could be established.

In addition, the HADS depression score at baseline was found to be positively associated to its follow-up score, indicating that carers who had experienced higher scores on the depression measure at baseline were also more likely to do so 12-months later. Both the relationship categories 'filial carers' and 'other unpaid carers' were significantly associated with the outcome variable. These results showed that the base category 'spouses,' in contrast with both filial carers and other unpaid carers, were more likely to experience higher depression scores at follow-up. Furthermore, from the six COPE categories tested, only the use of self-blame was found to be significantly associated with the HADS depression score. This suggests that unpaid carers who use self-blame as a coping mechanism at baseline were more likely to experience higher depression scores at follow-up. In addition, unpaid carers who experienced loneliness were also more likely to experience higher depression scores. Residuals of the model looked fine (see Box 6.4.2).

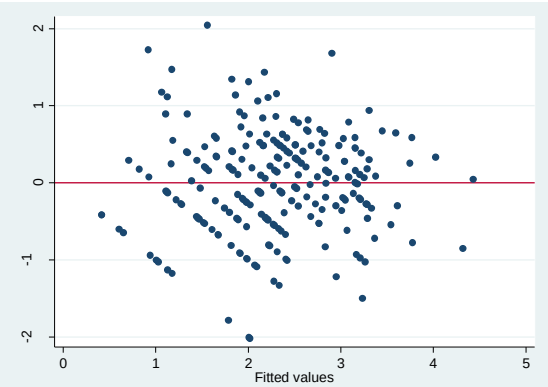
Table 6.4.2 multiple regression HADS 12-months depression score

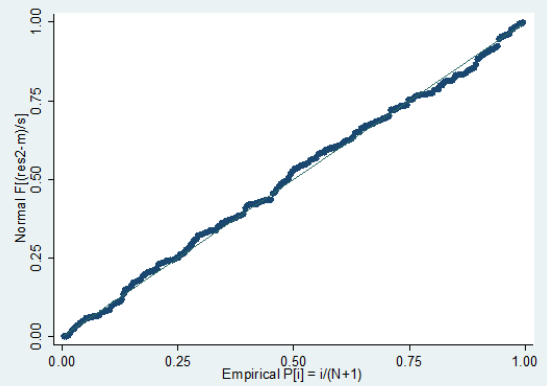
HADS depression 12 months	N=237; Imputations=5	
	Coefficient	95%CI
Carer gender		
Female	0.0119	-0.1929; 0.2168
Carer age	-0.0223**	-0.0374; -0.0072
Relationship		
Child	-0.7447***	-1.1541; -0.3352
Other	-0.5131**	-0.9796; -0.0466
Co-residence		
Yes		
HADS depression baseline	0.5664***	0.4481; 0.6847
PCS12	0.0132*	-0.0007; 0.0271
COPE self-blame	0.0941**	0.0178; 0.1704
Loneliness score	0.0514**	0.0031; 0.0997
Age care-recipient	0.0069	-0.0099; 0.0237
Randomisation		
Only CSP	0.0595	-0.2542; 0.3733
Only RYCT	-0.0555	-0.3363; 0.2253
SHIELD & CSP	-0.0783	-0.3596; 0.2029
Constant	1.4882**	0.3351; 2.6413

*p≤0.10 **p≤0.05 ***p≤0.0

Box 6.4.2 Overview residuals

Imputation 0





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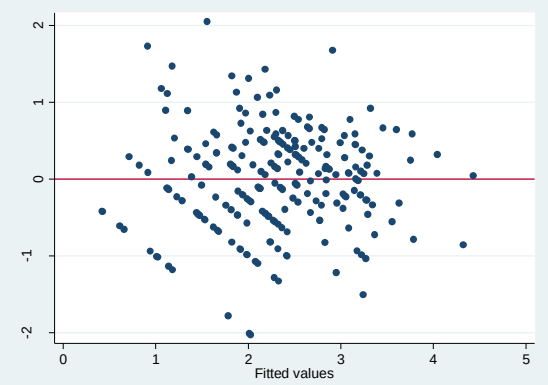
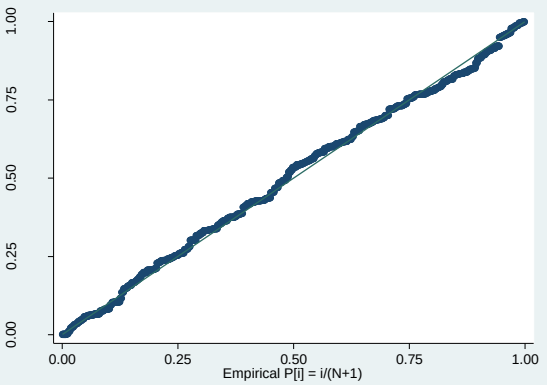
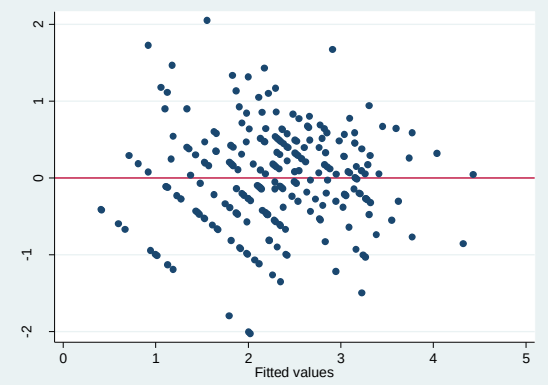
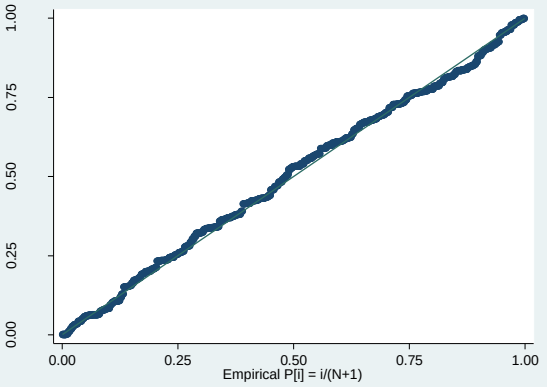




Imputation 4





The PGI Index

As with the other well-being and quality of life measures investigated, univariate analysis was also conducted for the Personal Growth Index (PGI) to select variables for the multiple regression model. Transformation of the variable did not improve normality of the distribution. The Personal Growth Index was found to be associated with time the co-resident can be left alone (18 to 24 hours) and the coping mechanism 'positive reframing'. The full table of the univariate analysis can be found in Appendix 5.4.1.

The best model for PGI model included 172 observations based on five imputations and showed no significant association with carer age or gender. The only significant association found in this model was with the PGI baseline score. The score was positively associated with the follow-up measure, suggesting that carers who expressed the experience of personal growth at baseline were also more likely to experience personal growth at follow-up. Residuals of the model did not give reason for concern (see Box 6.4.3).

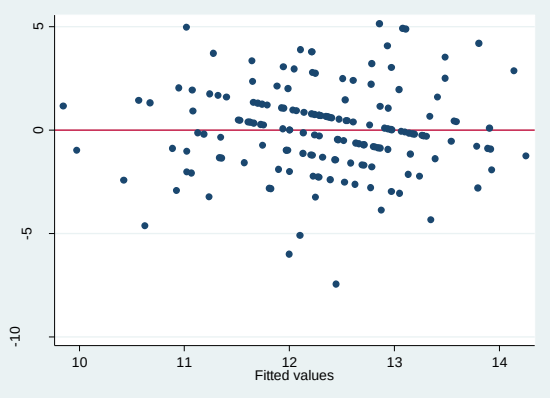
Table 6.4.3 multiple regression PGI 12-month score

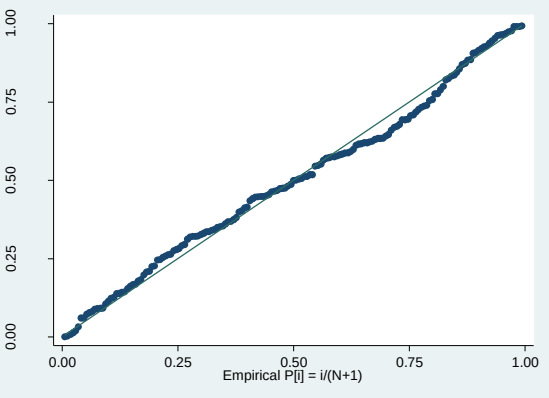
PGI 12 months	N=172; Imputations=5	
	Coefficient	95%CI
Gender		
Female	-0.5476	-1.2975; 0.2023
Age	0.0287	-0.0086; 0.0660
Time care-recipient can be left alone		
Six to less than 12 hours	-0.3225	-1.1143; 0.4693
12 hours to less than 18 hours	0.2935	-0.9957; 1.5828
18 to 24 hours	-1.7135	-3.8154; 0.3883
PGI baseline	0.1341**	0.0249; 0.2433
Severity		
Mild	0.1375	-1.1307; 1.4057
Moderate	0.5883	-0.7776; 1.9542
Severe	0.8735	-0.7030; 2.4501
Randomisation		
Only CSP	-0.5134	-1.6984; 0.6716
Only RYCT	0.6934	-0.4204; 1.8072
SHIELD &CSP	-0.1345	-1.2381; 0.9690
Constant	8.6111***	4.7922; 12.4299

*p≤0.10 **p≤0.05 ***p≤0.01

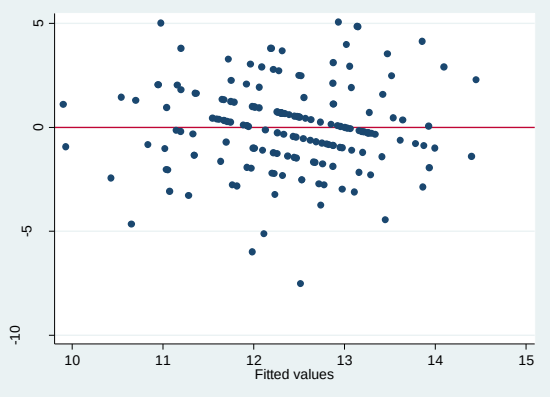
Box 6.4.3 Overview residuals

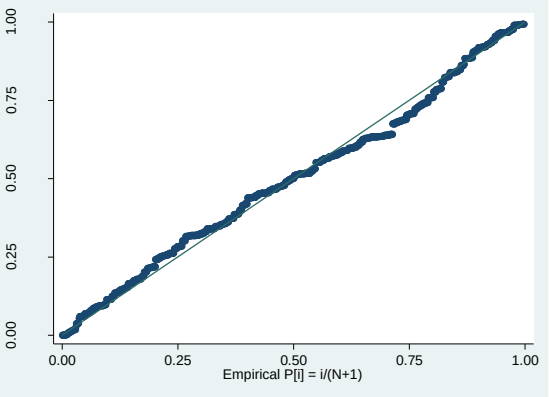
Imputation 0



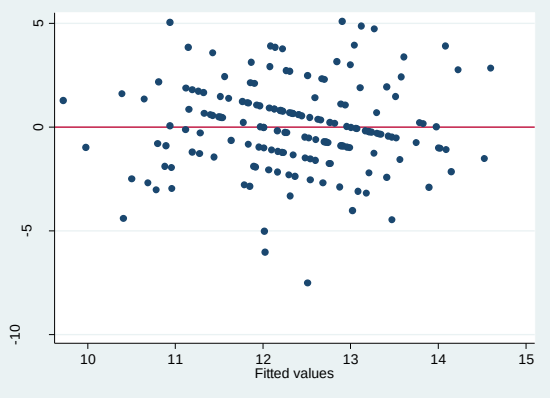


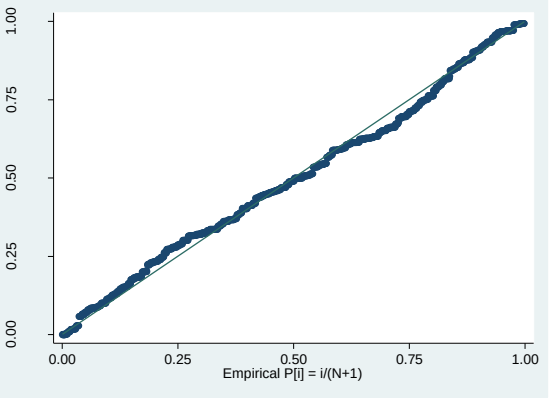
Imputation 1





Imputation 4





6.5 Analysis of MODEM

6.5.1 Complete case analysis

EQ-5D

As before, prior to analysis, the distribution of the outcome variable was investigated and EQ-5D was found to benefit from squaring. The simple regression analysis between the EQ-5D score at 12 month follow-up and a range of relevant variables at baseline showed significant associations for carer sleep-disruption due to the care needs, the Zarit burden score, carer self-rated health, carer chronic illness, the mental and physical health scores of the SF-12 questionnaire and receipt of carer counselling. Together with the pre-determined carer and care-recipient variables included in model 1 (see Appendix 5.5.1), these variables were introduced to model 2 in a stepwise fashion. The first multiple regression model exploring carer and care-recipient characteristics only found as significant association between EQ-5D baseline and follow-up scores.

The final model did not show a significant association between health-related quality of life at follow-up and carer age or gender. However, it revealed statistically significant negative associations between carers experiencing sleep-disruption due to the care needs and health-related quality of life, as well as for carers living with chronic illness. These findings suggest that those carers experiencing sleep-disruption and those living with a chronic illness were more likely to experience lower health-related quality of life at follow-up than carers who did not experience either of these issues. On the contrary, carers who indicated good quality of life at baseline were also more likely to experience higher health-related quality of life at follow-up. The only association between carer EQ-5D and care-recipient characteristics found to improve this model was care-recipient age. Carers supporting younger care-recipients were likely to experience lower health-related quality of life at 12-months than those looking after older people with dementia.

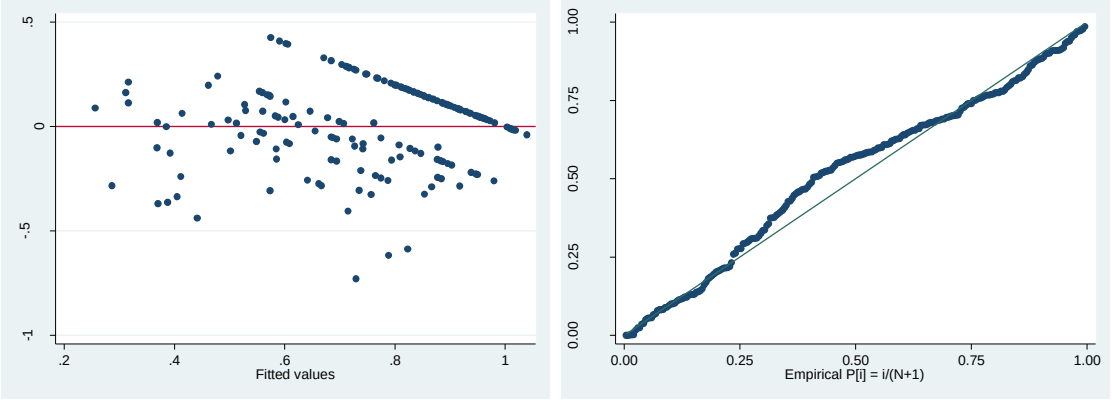
In order to explore whether residuals of the model can be improved, further transformation of the outcome variable was explored. However, no improvement was achieved. The residual plot in Box 6.5.1 does not indicate that the assumed linear relationship is unreasonable, nor any substantial problems with variance of the error term.

Table 6.5.1 multiple regression analysis with carer EQ-5D at 12-month as outcome variable

EQ-5D 12 months	N= 167	
	Coefficient	95%CI
Gender Female	0.0321	-0.0393; 0.1034
Age	0.0014	-0.0016; 0.0044
Carer sleep-disruption yes	-0.0791**	-0.1425; -0.0156
Carer chronic illness Yes	-0.1099**	-0.1828; -0.0372
EQ-5D baseline	0.4968***	0.3826; 0.6111
Age care-recipient	-0.0043*	-0.0086; 0.0001
Constant	0.6819***	-0.3308; 1.0329

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.5.1 Residuals



GHQ

Investigation of the GHQ scores showed that the variable would benefit from using a square-root transformation. The General Health Questionnaire scores of the carer at 12-month follow-up and the independent variables were then analysed using univariate analysis. Statistically significant associations were identified for carer gender, carer sleep-disruption due to care needs, the Zarit burden score, carer self-rated health, the physical and mental health component scores of the SF-12, receipt of carer counselling, receipt of carer allowance and support in the community. Among the variables representing characteristics of the care-recipient, statistically significant associations were found for care-recipient gender, NPI score and receipt of day-care. The first multiple regression models exploring

the relationship between GHQ at 12-months and carer and care-recipient characteristics showed statistically significant associations between the outcome measure and carer age, as well as with the variables age of the care-recipient and the GHQ baseline score (see Appendix 5.5.3).

In the final analysis, a positive statistically significant association between carer age and carer general health at follow-up was found, indicating that older carers were more likely to experience lower psychological health. No significant association between GHQ at 12 months and carer gender could be established. Other variables introduced into the multiple regression model also showed significant associations. Carers living with the care-recipient were more likely to rate their psychological health higher that those not living together with the person with dementia. Carers who rated their health as poor or very poor at baseline were found to experience lower psychological health scores on the GHQ measure at follow-up. Similarly, carers expressing less good mental health (GHQ) at baseline were more likely to rate their psychological health low at follow-up.

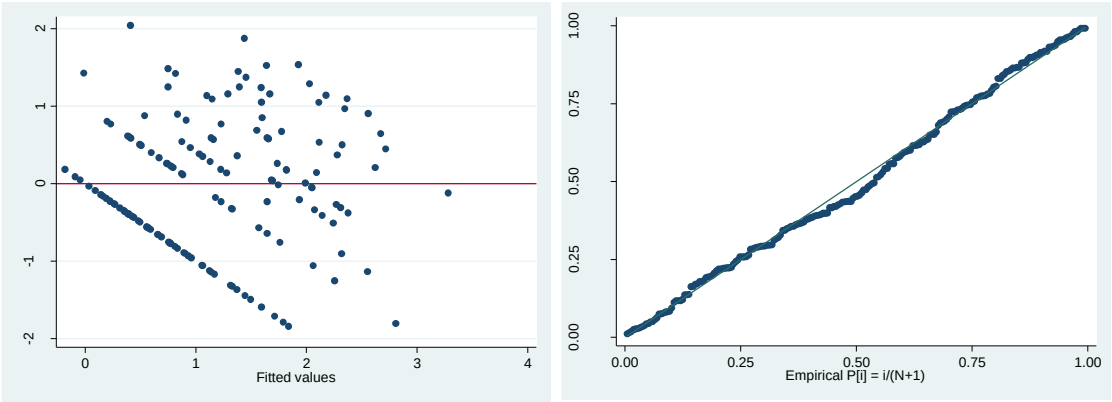
Attempts to improve residuals through further transformation of the outcome variables were unsuccessful. However, the residuals (Box 6.5.2) did not indicate any major concerns with respect to the underlying linear assumption of the model or the variance of the error term.

Table 6.5.2 multiple regression analysis with carer GHQ at 12-month as outcome variable

GHQ 12 months	N= 154	
	Coefficient	95%CI
Gender		
Female	0.0881	-0.2243; 0.4005
Age	0.0195**	0.0032; 0.0358
Co-residence		
yes	-0.5007**	-0.9863; -0.0150
Carer health		
Good	0.3165*	-0.0151; 0.6480
Poor and very poor	0.7572**	0.3021; 1.2122
GHQ baseline	0.4497***	0.3031; 0.5963
Carer allowance		
yes	0.3617*	-0.0178; 0.7412
Day-care		
yes	0.3489**	0.0687; 0.6290
NPI	0.0091	-0.0016; 0.0198
Constant	-1.0838	-2.2072; 0.0395

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.5.2 Residuals



Personal well-being questions

As described in Chapter 3.5.1, we introduced four questions that would allow us to investigate components of personal well-being in the MODEM follow-up questionnaire. Since these variables were only introduced at follow-up the following regression analyses do not contain the personal well-being variables at baseline. Normality of the personal well-being variables one to three was improved by squaring, while the personal well-being question four was found to be best analysed in its normal form.

PWB1: 'Overall, how satisfied are you with life nowadays'

The first personal well-being questions asked carers to rate the question 'Overall, how satisfied are you with life nowadays?' The univariate regression analyses revealed associations between this measure and carer gender, Zarit burden score, carer self-rated health, the experience that caring affected the carer's health, the mental and physical health scores of the SF12, receipt of carers counselling and carer allowance. Significant associations were also found for three variables related to the carer recipient, including gender of the care-recipient, dementia severity and NPI. The first multiple regression model exploring the relationship between life satisfaction and carer and care-recipient characteristics did not find any statistically significant relationships (see Appendix 5.5.3).

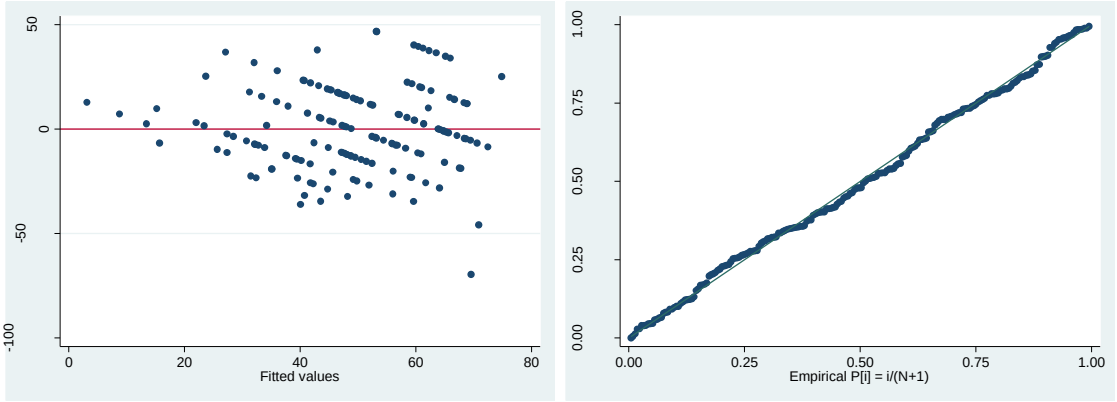
The final model, however, showed a negative statistically significant association with carer gender. This suggested that women were less likely to express satisfaction with their life than men. No association was found for carer age. Among other variables revealing significant associations were carer self-rated health and the mental health component of the SF-12. Carers who experienced good, poor or very poor health at baseline were less likely to rate high life satisfaction compared to those rating their health as very good. Similarly, carers who experienced low scores on the SF-12 mental health score were less likely to rate their life satisfaction high. Furthermore, carers in receipt of carer allowance at baseline were less likely to provide a high life satisfaction rating at follow-up. On the other hand, carers supporting older people with dementia were more likely to rate their life satisfaction higher. The residual plot in Box 6.5.3 gave no substantial concern about the underlying linear assumption or the variance of the error term.

Table 6.5.3 multiple regression analysis with carer PWB1 at 12-month as outcome variable

PWB1 12 months	N= 151	
	Coefficient	95%CI
Gender		
Female	-9.4077**	-17.4332; -1.3822
Age	-0.0563	-0.3900; 0.2774
Carer health		
Good	-9.8913**	-17.8711; -1.9115
Poor and very poor	-19.5017**	-30.9223; -8.0810
SF12 Mental health	0.7356***	0.3797; 1.0914
Carer allowance		
yes	-12.2364**	-21.5649; -2.9079
Severity		
Moderate	-3.6067	-11.1638; 3.9504
Severe	-1.1334	-11.0972; 8.8303
Age care-recipient	0.5609**	0.0949; 1.0269
Constant	-6.7042	-48.3330; 34.9247

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.5.3 Residuals



PWB2: ‘Overall, to what extent do you feel that the things you do in your life are worthwhile?’

The second personal well-being question investigated eudaimonic well-being with the question ‘Overall, to what extent do you feel that the things you do in your life are worthwhile?’ Univariate regression analysis suggested investigating the Zarit burden score, carer self-rated health, chronic illness, the feeling that carer health was affected through dementia care provision, the mental and physical health components of the SF-12, the presence of other carers and supporting a person with moderate dementia. The first multiple regression model exploring the relationship between this well-being measure and a set of carer and care-recipient characteristics only showed a statistically significant relationship between the outcome measure and providing care for a person with moderate dementia.

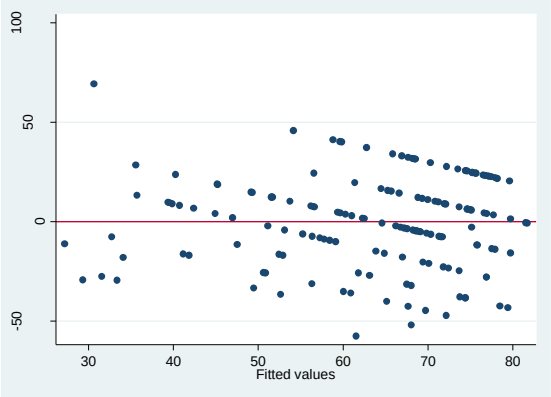
The final model did not find a significant association with carer age or gender. Instead, it was found that carers who rated their health as poor and very poor at baseline were less likely to feel that things in their life were worthwhile compared to those rating their health as very good. Similarly, carers experiencing poor mental health also were less likely to experience the things they do as worthwhile. Furthermore, carers supporting someone with moderate dementia also were less likely to experience their daily life as worthwhile compared to those looking after a person with mild dementia. No statistically significance was found for carers supporting people with severe dementia. The residuals of this model (Box 6.5.4) seemed fine, suggesting that the assumption of a linear relationship was reasonable and that the variance of the error terms were equal.

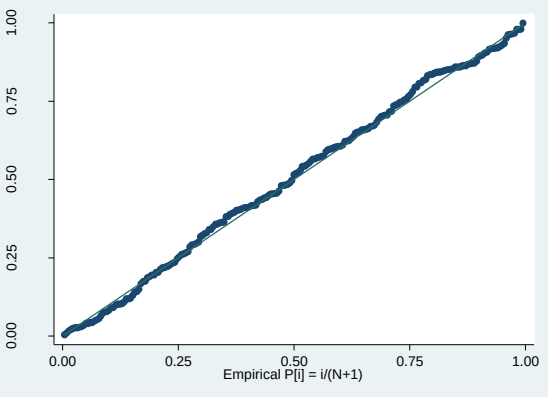
Table 6.5.4 multiple regression analysis with carer PWB2 at 12-month as outcome variable

PWB2 12 months	N= 158	
	Coefficient	95%CI
Gender		
Female	0.3680	-8.3204; 9.0565
Age	0.1534	-0.2187; 0.5255
Carer health		
Good	-4.2819	-13.4003; 4.8365
Poor and very poor	-24.1433***	-37.0373; -11.2492
SF12 Mental health	0.4265**	0.0117; 0.8413
Health affected		
Yes	-2.3636	-11.8972; 7.1699
Severity		
Moderate	-9.7906**	-18.1713; -1.4098
Severe	3.4296	-8.3539; 15.2131
Constant	43.2918**	9.9155; 76.6681

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.5.4 Residuals





PWB3: 'Overall, how happy did you feel yesterday?'

The third well-being question in MODEM investigated carers overall happiness (hedonic well-being). In addition to the pre-determined carer and care-recipient variables, univariate analysis suggested investigating carer marital status, carer education, the OARS scale, the Zarit burden score, carer self-rated health, carer health affected due to care, the mental health score of the SF-12, receipt of counselling and carer allowance as well as dementia severity of the care-recipient and the NPI score. The first regression model did

not find any associations between carer happiness at 12-month follow-up and a set of carer and care-recipient characteristics (see Appendix 5.5.4).

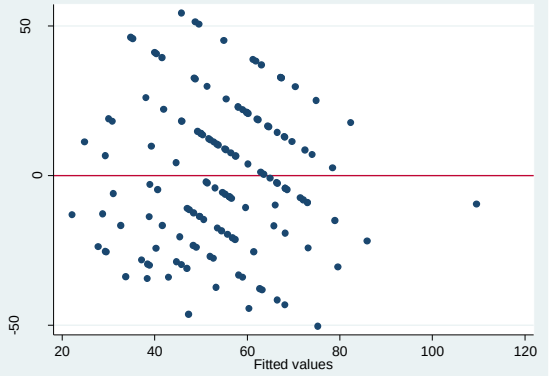
The final model, similarly to the model investigating life satisfaction, showed that female carers were less likely to express happiness than men. No statistically significant difference could be found for carer age. The other variables in the model found to be associated with carer happiness were the OARS scale and care-recipient behaviour (NPI). Carers rating their social resources to be severely or totally impaired were significantly less likely to indicate happiness than those whose social resources were not affected. Furthermore, carers whose care-recipient exhibited more challenging behaviour were less likely to express happiness at follow-up than those whose relatives with dementia did this less. The residual plot (Box 6.5.5) did not indicate any substantial problems with regards to linearity or variance of error terms.

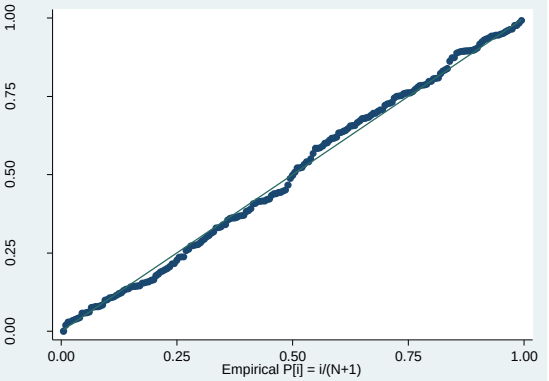
Table 6.5.5 multiple regression analysis with carer PWB3 at 12-month as outcome variable

PWB3 12 months	N= 144	
	Coefficient	95%CI
Gender		
Female	-12.2572**	-23.0981; -1.4164
Age	-0.6677	-1.5805; 0.2450
Relationship		
Filial carer	-24.7079*	-49.7678; 0.3519
Other unpaid carers	19.0371	-15.4112; 53.4853
OARS		
Mildly and moderately socially impaired	-9.7532*	-21.2939; 1.7875
Severely and totally socially impaired	-12.6829**	-24.8017; -0.5640
Health affected		
yes	-6.2352	-16.2736; 3.8032
Carer allowance		
Yes	-5.3613	-17.4983; 6.7757
Severity		
Moderate	-4.9857	-14.5756; 4.6042
Severe	15.8749	1.4466; 30.3033
NPI	-0.5742**	-0.9142; -0.2342
Constant	30.7053	-19.4827; 80.8932

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.5.5 Residuals





PWB4: 'On a scale, where nought is 'not at all anxious' and 10 is 'completely anxious', overall, how anxious did you feel yesterday?'

The fourth personal well-being question investigated carers' experience of anxiety. Significant associations in the univariate models were found for the variables Zarit burden score, self-rated carer health, the mental health component of the SF-12 and care-recipient challenging behaviour measured through the NPI. No statistically significant differences were found exploring the relationship between carers' level of anxiety and a number of carer and care-recipient characteristics (see Appendix 5.5.4).

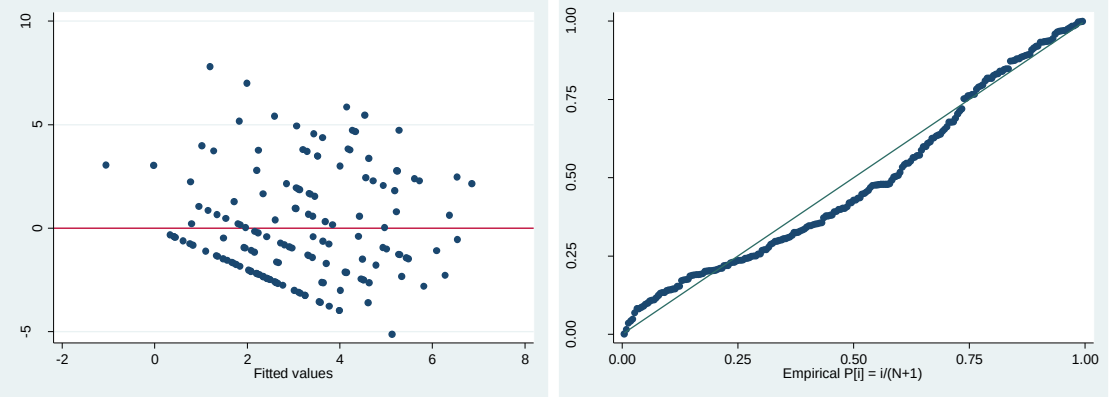
Following the stepwise procedure, the final model revealed that older carers experience greater levels of anxiety. No statistically significant difference was found for carer gender. In addition, carers who expressed their health to be good were more likely to feel anxious than carers who rated their health as very good. Similarly, carers who rated their mental health higher were less likely to experience anxiety. Carers supporting older care-recipients were less also likely to express anxious feelings compared to those caring for younger care-recipients. As before, residuals plots presented in Box 6.5.6 did not point towards major problems with respect to linearity or variance of error terms.

Table 6.5.6 multiple regression analysis with carer PWB4 at 12-month as outcome variable

PWB4 12 months	N= 158	
	Coefficient	95%CI
Gender		
Female	0.6056	-0.4249; 1.6361
Age	0.0604**	0.0173; 0.1035
Carer health		
Good	1.2959**	0.2574; 2.3346
Poor and very poor	0.5896	-0.8802; 2.0595
Carer health affected		
Yes	-0.1196	-1.2091; 0.9699
SF12 Mental health	-0.1321***	-0.1794; -0.0848
Age care-recipient	-0.0652**	-0.1237; -0.0066
Severity		
Moderate	-0.3161	-1.2702; 0.6379
Severe	0.2897	-1.0734; 1.6528
Constant	9.1026**	3.7445; 14.4606

*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.5.6 Residuals



6.5.2 Imputation

As in START, I also identified missing values for MODEM in both outcome and independent variables, operating under the assumption that data in MODEM was missing at random (see Chapter 3.5.2). The same process as outlined for START (see Section 6.3.2) was followed for MODEM data.

At the time when I started working on the imputation of the MODEM data for this chapter, other parts of the wider MODEM project also required imputation. Given the benefit of introducing auxiliary variables, and for coherence of the overall project, we decided to jointly impute data for the overall project need and for the needs of this analysis. The variables included in the imputation model can be found in Table 7.5.7.

Outcome variables of interest for this analysis were EQ-5D, GHQ and the four personal well-being questions at 12-month follow-up. The proportion of missingness among these variables ranged from 26% to 23.5%. For this reason we decided to run twenty imputations. As in START, I decided to only impute summary scores for EQ-5D and GHQ 12 as the EQ-5D score was only available in this form, and individual GHQ 12 item scores were highly correlated to the overall GHQ 12 score. The personal well-being scores were analysed as item scores and therefore imputed as such. As in START, multiple imputations by chained equations were used to impute the data.

Despite exploring different routes to imputing the data, we were unable to fully impute all of the variables. However, when we investigated the distribution and maximum and minimum values of the imputed data, the imputed data seemed fine. Similarly, investigating the Monte Carlo error, as described in Section 6.3.2, did not indicate any problems with the imputation model.

Imputed MODEM data was analysed for a number of separate imputations as outlined in Section 6.3.2. Combined models are presented in this chapter.

Table 6.5.7 Overview of multiple imputations

Variable	Complete	Incomplete	Imputed	Total
EQ-5D 12 months	243	76	31	319
Carer age	271	48	1	319
Care-recipient age	273	46	0	319
Other carers	272	47	0	319
EQ-5D baseline	267	52	5	319
GHQ 12 months	244	75	30	319
GHQ baseline	269	50	3	319
Carer marital status	250	69	21	319
SF12 baseline physical health	261	58	11	319
SF12 baseline mental health	261	58	11	319
NPI baseline	257	62	17	319
OARS rating baseline	258	61	13	319
Dementia severity	269	50	0	319
PWB1	236	83	36	319
PWB2	238	81	35	319
PWB3	238	81	35	319
PWB4	238	81	35	319
Carer self-rated health	269	50	3	319
Zarit baseline	268	51	4	319
Other care-recipient	270	49	2	319
Memory function care-recipient	136	183	124	319
Executive function care-recipient	135	184	125	319
Literacy skills care-recipient	109	210	149	319
Numeracy skills care-recipient	136	183	124	319
Cost of accommodation 12 months	275	44	3	319
Total formal social care cost 12 months	218	101	55	319
Total formal social care cost 12 months (specific services)	219	100	54	319
NHS costs 12 months	274	45	4	319
Relationship to care-recipient	273	46	1	319
Carer allowance baseline	263	56	7	319
Carer cash baseline	264	55	6	319
Carer community services baseline	271	48	1	319
Carer health affected due to care demands	269	50	3	319
Carer lives with chronic illness	271	48	1	319
Carer employment	271	48	1	319
Community services 12 months	247	72	26	319

6.5.3 MODEM analysis using imputed data

Following the imputation of the data, models presented in the complete case analysis were re-built using the imputed data. Where variables were transformed for the complete case analysis to improve normality of the distribution, these transformations were also found to improve the distribution of the outcome variables following imputation and were maintained for the analysis.

EQ-5D

As before, variables considered for the multiple regression model were the pre-determined carer and carer recipient characteristics as well as variables that showed a significant association in the univariate analysis. In this case, the variables considered from the univariate analysis were carer sleep-disruption, the Zarit burden score, carer self-rated health, chronic illness, the physical health score of the SF-12 and carer receipt of counselling (see Appendix 5.5.5). A first model exploring associations between health-related quality of life at follow-up and carer and care- recipient characteristics only found a relationship between EQ-5D baseline and follow-up (see Appendix 5.5.7).

The final model investigating health-related quality of life over the course of 12 months contained 196 observations and showed no significant relationship for carer gender or age. Instead, it was found that carers who experienced sleep-disruption at baseline due to care needs of their relative with dementia had significantly lower EQ-5D scores at follow-up. In addition, it was found that carers who indicated good physical health through the SF-12 questionnaire and those who scored higher on the EQ-5D questionnaire at baseline were also more likely to experience greater health-related quality of life one year on. Among the care-recipient variables, carer recipient age was negatively associated with the outcome measures suggesting that those caring for a younger person with dementia were more likely to declare lower health-related quality of life. Further transformation of the outcome variable was explored, however, did not improve residuals for this model (see Box 6.5.8).

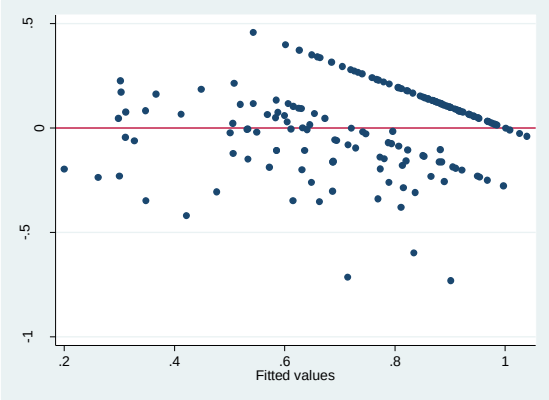
Table 6.5.8 EQ-5D model: multiple regression analysis using imputed data

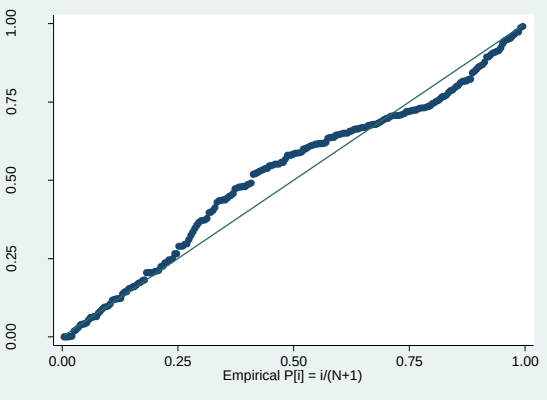
EQ-5D 12 months	N=196; Imputations=20	
	Coefficient	95%CI
Gender Female	0.0189	-0.0495; 0.0874
Age	0.0032	-0.0008; 0.0072
Co-residence yes	-0.0446	-0.1669; 0.0778
Carer sleep-disruption Yes	-0.0671**	-0.1303; -0.0038
Physical health carer	0.0071***	0.0033; 0.0109
EQ-5D baseline	0.3695***	0.2209; 0.51811
Age care-recipient	-0.0050**	-0.0096; -0.0004
Constant	0.3715*	-0.0003; 0.7434

*p≤0.10 **p≤0.05 ***p≤0.01

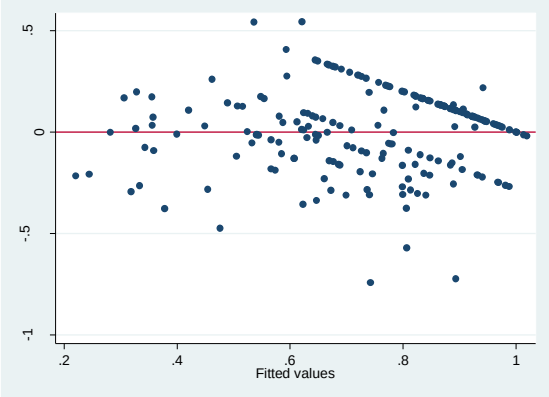
Box 6.5.8 Residuals

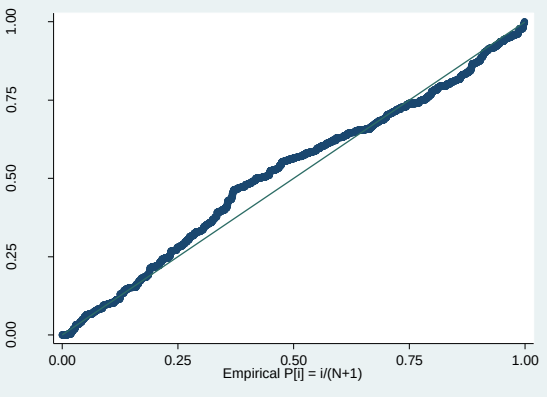
Imputation 0



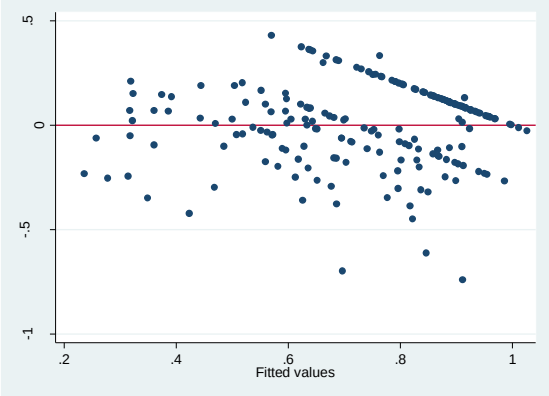


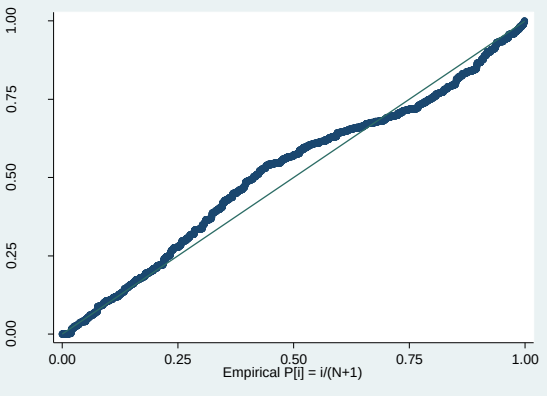
Imputation 4





Imputation 15





GHQ

Univariate regression analyses suggested introducing the variables carer gender, sleep-disruption due to care needs, Zarit burden score, carer self-rated health, chronic illness, carers' perception that the provision of care had affected their health as well as the receipt of counselling, carer allowance and community support. In addition, experiencing challenging behaviour from the care-recipient (NPI) and care-recipient receipt of medical services in the community was found to be significantly associated with GHQ at 12 months follow-up. The first model, presented in Appendix 5.5.7, found no statistically significant associations between the GHQ and carer or care-recipient characteristics; however, a significant association was found between GHQ baseline and follow-up scores. These variables and the carer and care-recipient variables explored in the first model were introduced to the model in a stepwise fashion as outline in Chapter 3.5.3.

The final model included 181 observations. It showed no statistically significant association between the GHQ measure at 12 months and carer gender and age. The significant association with age observed in the complete case analysis was lost after imputation. It was found, however, that carers rating their health as poor or very poor experienced lower general health than carers who rated their health as very good. Similarly, carers who had rated their general health low at baseline were also more likely to experience lower general health at follow-up. These results are consistent with the complete case analysis model. Transformation of the outcome variable did not improve the residuals (see Box 6.5.9).

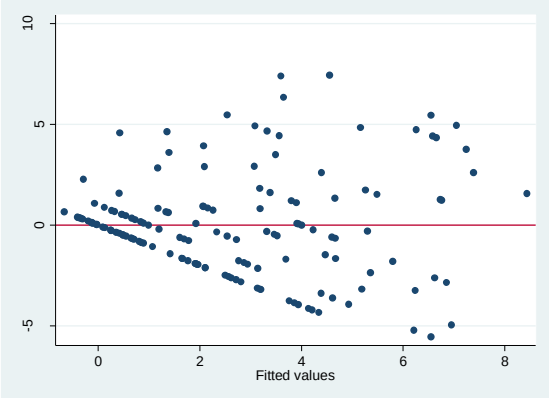
Table 6.5.9 GHQ model: multiple regression analysis using imputed data

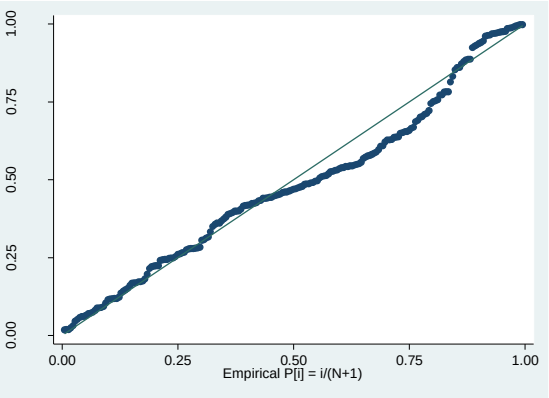
GHQ 12 months	N=181; Imputations=20	
	Coefficient	95%CI
Gender		
Female	0.5236	-0.4272; 1.4745
Age	0.0216	-0.0300; 0.0732
Co-residence		
yes	-0.5905	-2.1165; 0.9354
Self-rated health		
Good	0.6486	-0.4019; 1.6991
Poor and very poor	2.3015**	0.7883; 3.8146
Chronic illness		
Yes	0.1212	-0.8984; 1.1407
Receipt of carer allowance		
Yes	0.7652	-0.4313; 1.9617
GHQ baseline	1.2921***	0.8242; 1.7599
NPI	0.0172	-0.0181; 0.0525
Severity		
Moderate	0.4387	-0.5071; 1.3845
Severe	0.4174	-1.0428; 1.8776
Constant	-1.7488	-5.1669; 1.6692

*p≤0.10 **p≤0.05 ***p≤0.01

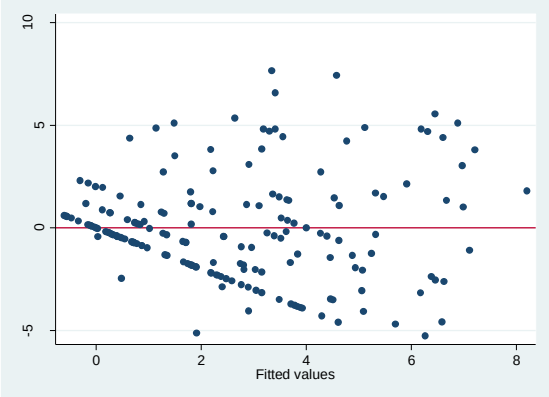
Box 6.5.9 Residuals

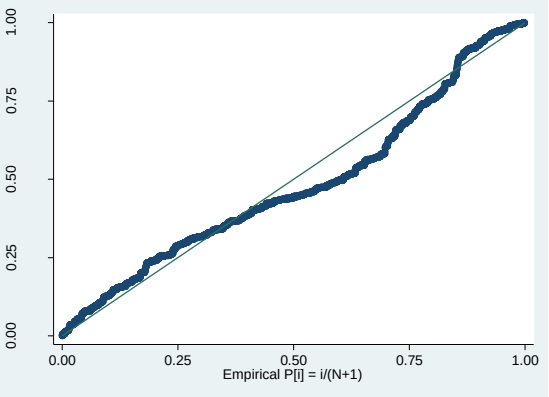
Imputation 0



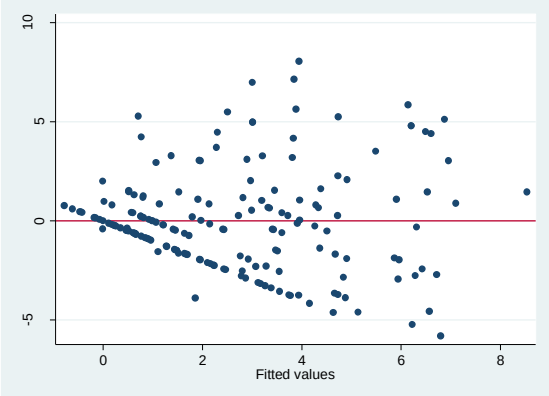


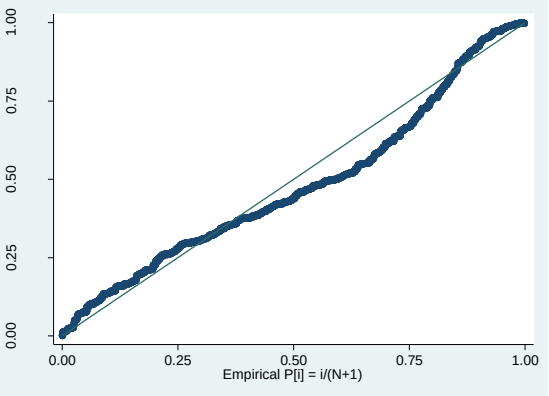
Imputation 4





Imputation 15





PWB1: 'Overall, how satisfied are you with life nowadays'

The first personal well-being question, following imputation, showed statistically significant associations in the univariate analyses with the variables carer gender, the Zarit burden score, carer self-rated health, carers experiencing caring as affecting their health, the physical and mental health score from the SF-12, receipt of counselling and carer allowance as well as the gender of the care-recipient, dementia severity and the experience of challenging behaviour by the person with dementia (NPI). A first model investigating associations between life satisfaction and carer and care-recipient characteristics did not show any statistically significant associations (see Appendix 5.5.7). Together with the carer and care-recipient variables explored in the first model, these were analysed for the final model.

The final imputed model included 194 observations. No statistically significant relationship between life satisfaction at 12-months and carer age and gender could be established. The model, however, showed that carers in receipt of carer allowance at baseline were less likely to be satisfied with life at follow-up. The two component-scores mental and physical health of the SF-12 measure showed that carers who experienced good mental and physical health at baseline also were more likely to be satisfied with their life at follow-up. These results were overall consistent with the complete case analysis. The residual plots of the model did not give reason for concern (see Box 6.5.10).

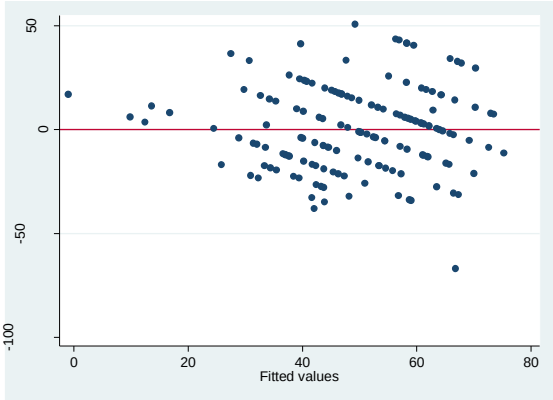
Table 6.5.10 PWB1 model: multiple regression analysis using imputed data

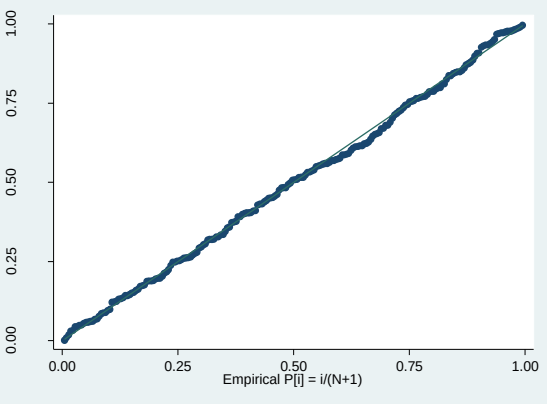
PWB1 12 months	N=194; Imputations=20	
	Coefficient	95%CI
Gender		
Female	-7.0861*	-15.3977; 1.2255
Age	0.0032	-0.3997; 0.4060
Receipt of carer allowance		
Yes	-12.2064**	-21.8149; -2.5979
SF 12 physical health	0.3639**	0.0364; 0.6913
SF 12 mental health	0.9347***	0.5712; 1.2982
Age care-recipient	0.4553*	-0.0692; 0.9797
Severity		
Moderate	-0.9627	-9.2257; 7.3004
Severe	0.1113	-10.3283; 10.5509
Constant	-40.5111	-92.6038; 11.5816

*p≤0.10 **p≤0.05 ***p≤0.01

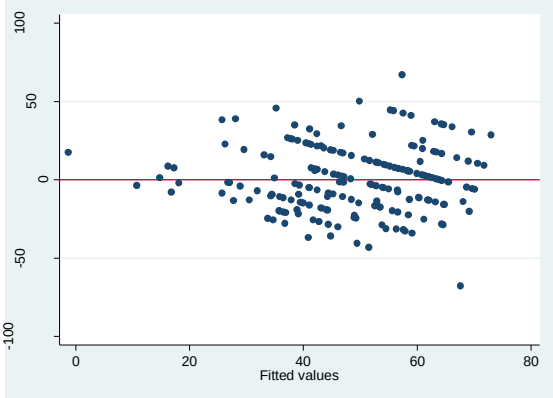
Box 6.5.10 Residuals

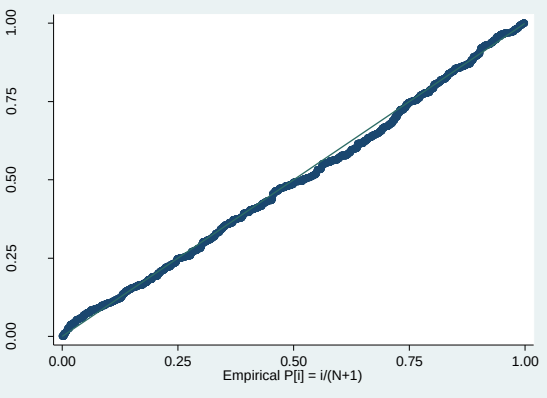
Imputation 0



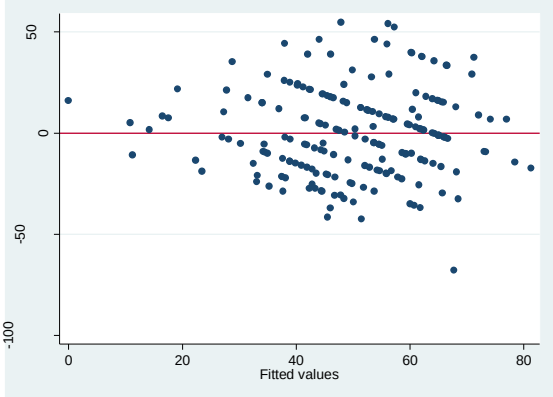


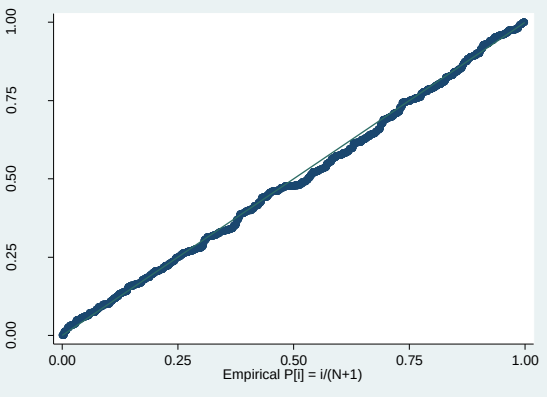
Imputation 4





Imputation 15





PWB2: ‘Overall, to what extent do you feel that the things you do in your life are worthwhile?’

The second personal-well-being question investigated eudaimonic well-being by asking carers how worthwhile they feel the things they do in life are. This outcome measure showed significant associations in the univariate analyses with the variables Zarit burden score, carer self-rated health, perceived health impacts due to care, the mental and physical health components of the SF-12 and receipt of counselling. The first regression model investigating relationships between the well-being outcome measure and carer and care-recipient characteristics did not show any statistically significant associations (see Appendix 5.5.8).

Stepwise regression analysis of these variables as well as the carer and care-recipient characteristics explored in the first model found the best model to include the variables carer gender, age, carer self-rated health, the Zarit burden score and dementia severity of the care-recipient. The imputed model consisting of 194 observations did not find a significant association between carer age and gender. Carer self-rated health and the Zarit burden score, however, were negatively associated with the personal well-being measure at follow-up, suggesting that carers who described their health as poor or very poor at baseline were less likely to feel that things they did in their lives were worthwhile at follow-up. Similarly, carers who had experienced challenging behaviour by their relative with dementia were less likely to rate their everyday life as worthwhile. The relationship between self-rated health and the outcome measure was also observed in the complete case analysis; the Zarit measure had not been included in the complete case analysis model. Residuals of the model were not improved by further transformation of the outcome variable (see Box 6.5.11).

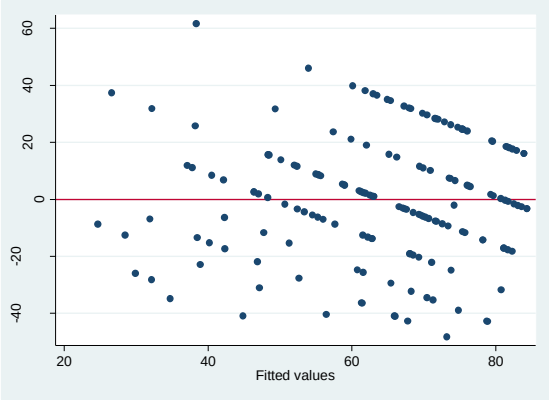
Table 6.5.11 PWB2 model: multiple regression analysis using imputed data

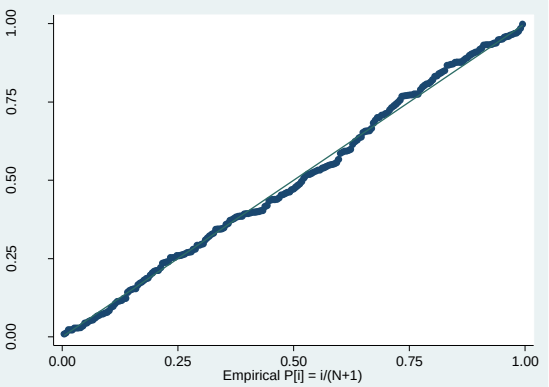
PWB2 12 months	N=194; Imputations=20	
	Coefficient	95%CI
Gender		
Female	0.5986	-7.6493; 8.8465
Age	0.1844	-0.1912; 0.5600
Carer health		
Good	-4.3781	-13.6797; 4.9235
Poor and very poor	-23.1319***	-35.2668;-10.9972
ZARIT	-0.6242***	-0.9403; -0.3081
Severity		
Moderate	-3.7573	-12.6764; 5.1619
Severe	4.9622	-6.2245; 16.1489
Constant	76.5443***	45.3547; 107.734

*p≤0.10 **p≤0.05 ***p≤0.01

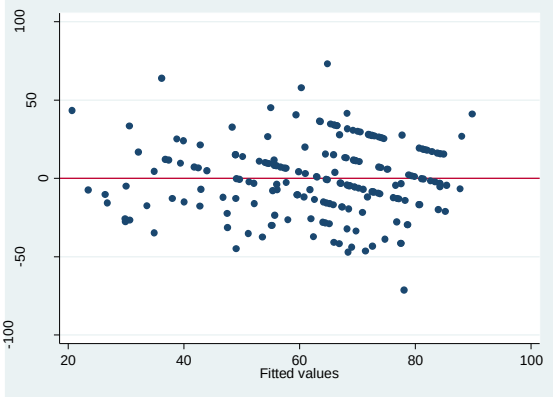
Box 6.5.11 Residuals

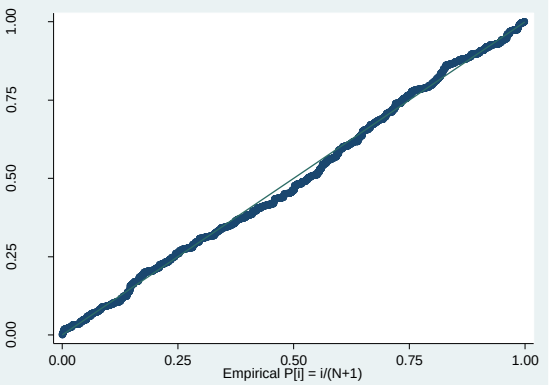
Imputation 0



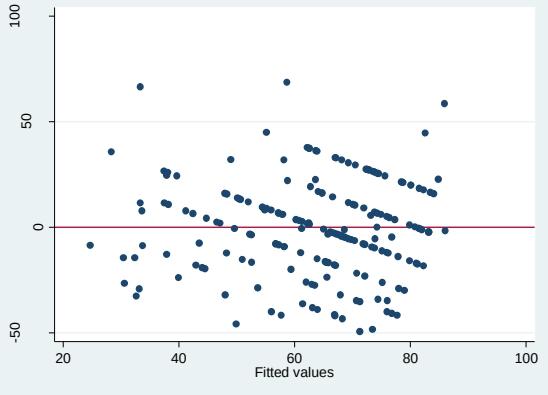


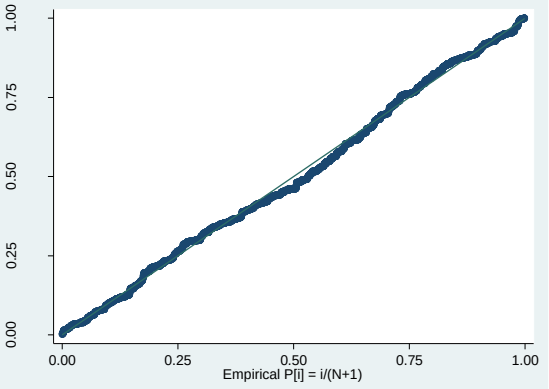
Imputation 4





Imputation 15





PWB3: ‘Overall, how happy did you feel yesterday?’

Hedonic well-being, measured through the third personal well-being question focusing on happiness found carer education, the OARS measure, carer self-rated health, the perception that carers health was affected by caring for the person with dementia, the mental health score of the SF-12, the receipt of carer counselling and the receipt of carer allowance to be associated in the univariate analysis. In addition, severity of dementia in the care-recipient and the experience of challenging behaviour by the relative with dementia were found to be significantly associated. A first regression model exploring associations between carer happiness and carer and care-recipient characteristics found statistically significant relationships with the variables age of the care-recipient and providing care for a person with moderate dementia (see Appendix 5.5.8).

The final imputed model exploring these variables as well as the carer and care-recipient characteristics explored in the first model using a stepwise approach included 194 observations. As in the other three personal well-being questions explored in MODEM, no significant association was found for the variables carer age or carer gender. In fact, the only statistically significant association in this model was with the baseline mental health score of the SF-12 measure. This finding suggests that carers who experienced good mental health at baseline were also more likely to express greater happiness at follow-up. The relationship between carer happiness and the caring for a person with moderate dementia, observed in the first model, was lost in the final model. Residuals of the model were found to be acceptable (see Box 6.5.11).

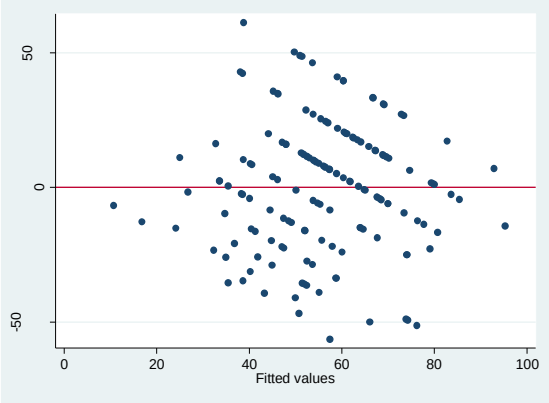
Table 6.5.12 PWB3 model: multiple regression analysis using imputed data

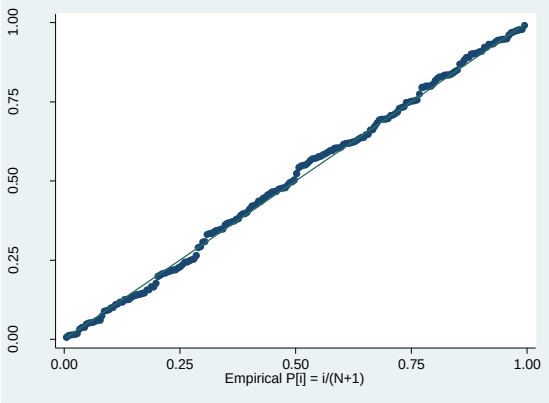
PWB3 12 months	N=194; Imputations=20	
	Coefficient	95%CI
Gender		
Female	-3.4636	-13.0384; 6.1111
Age	0.2347	-0.4233; 0.8926
Relationship		
Filial carer	5.8316	-11.4019; 23.0652
Other unpaid	21.1605	-9.7939; 52.1149
Co-residence		
Yes	7.8983	-10.7207; 26.5173
OARS		
Mildly and moderately socially impaired	-8.8569	-22.0597; 4.3459
Severely and totally socially impaired	-11.8659*	-24.4754; 0.7434
SF 12 mental health	0.8906***	0.4596; 1.3215
Receipt carer allowance		
Yes	-9.7008*	-20.9639; 1.5622
Severity		
Moderate	-6.4245	-15.5186; 2.6697
Severe	2.8637	-9.6935; 15.4209
Constant	2.7162	-47.4406; 52.8730

*p≤0.10 **p≤0.05 ***p≤0.01

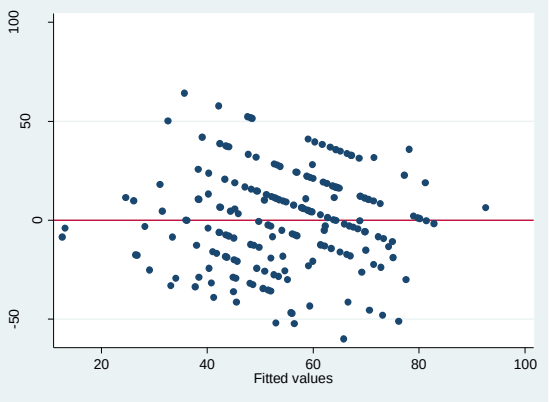
Box 6.5.12 Residuals

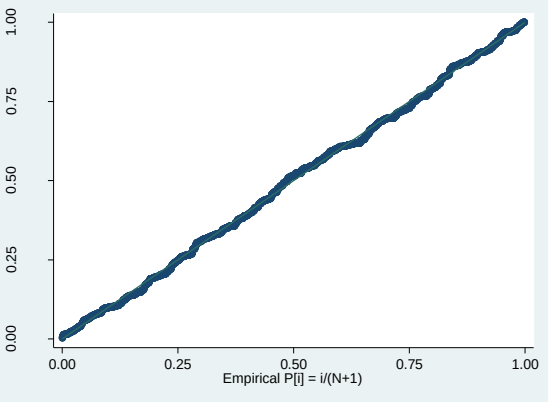
Imputation 0



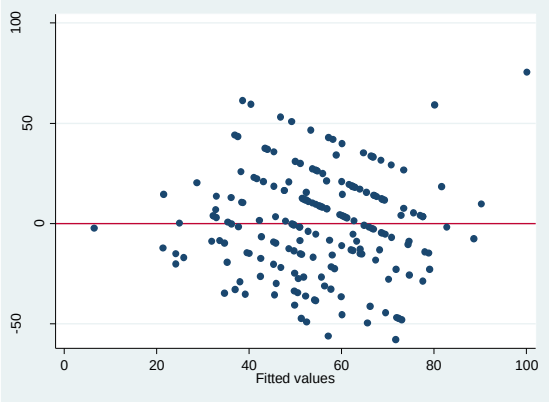


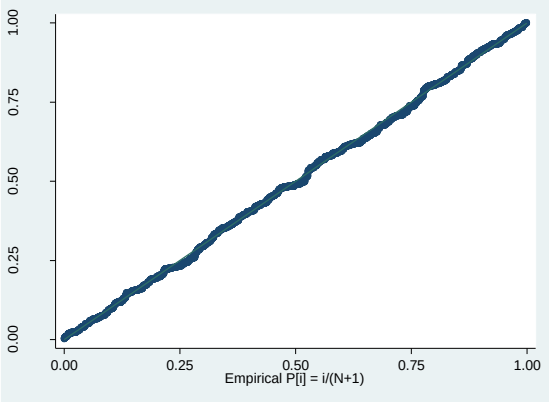
Imputation 4





Imputation 15





PWB4: ‘On a scale, where nought is ‘not at all anxious’ and 10 is ‘completely anxious’, overall, how anxious did you feel yesterday?’

The final personal well-being question investigating feelings of anxiety found significant associations with the Zarit burden score, carer self-rated health, the mental health score of the SF-12 and challenging behaviour of the care-recipient (NPI) in the univariate analyses. A first regression model exploring the relationship between carer anxiety and a number of carer and care-recipient characteristics did not show any statistically significant associations (see Appendix 5.5.8).

Following the stepwise approach used in this chapter to determine the best model, no statistically significant associations could be established for the variables carer age or gender. This model contained of 181 observations. The analysis, however, found significant associations for the variables carer self-rated health, age of the care-recipient and experience of challenging behaviour by the person with dementia. The association between the personal well-being question four and carer age that was observed in the complete case analysis was lost following the imputations. In comparison to carers rating their health as very good, carers with good self-rated health were more likely to feel anxious. Similarly, carers, whose relatives with dementia exhibited challenging behaviour, were more likely to experience anxious feelings. A significant relationship emerged for the variable age of the care-recipient, suggesting that carers of older people with dementia experienced less anxiety. Transformation of the outcome variable did not improve the residuals of the model (see Box 6.5.12).

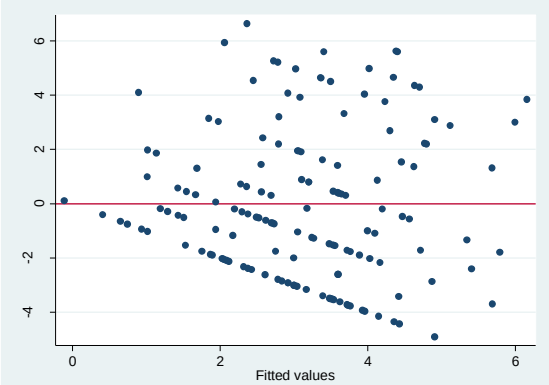
Table 6.5.13 PWB4 model: multiple regression analysis using imputed data

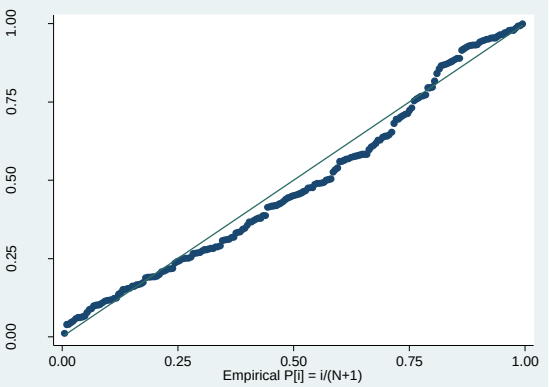
PWB4 12 months	N=194; Imputations=20	
	Coefficient	95%CI
Carer Gender		
Female	0.9956*	-0.0843; 2.0754
Carer age	0.0373*	-0.0070; 0.0816
Carer health		
Good	1.4989**	0.4030; 2.5948
Poor and very poor	0.9525	-0.6584; 2.5633
OARS		
Mildly and moderately socially impaired	0.4245	-0.9778; 1.8269
Severely and totally socially impaired	0.9581	-0.4322; 2.3485
Age care-recipient	-0.0801**	-0.1443; -0.0158
NPI	0.0459**	0.0082; 0.0835
Severity		
Moderate	-0.3269	-1.3630; 0.7092
Severe	-0.6032	-2.1779; 0.9716
Constant	4.0996	-1.5010; 9.7003

*p≤0.10 **p≤0.05 ***p≤0.01

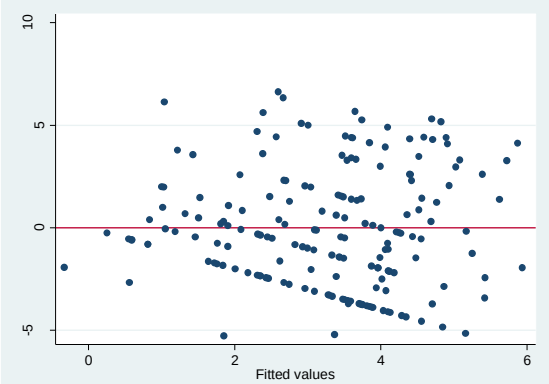
Box 6.5.13 Residuals

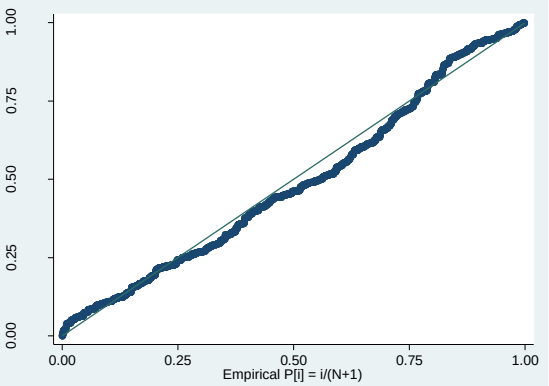
Imputation 0



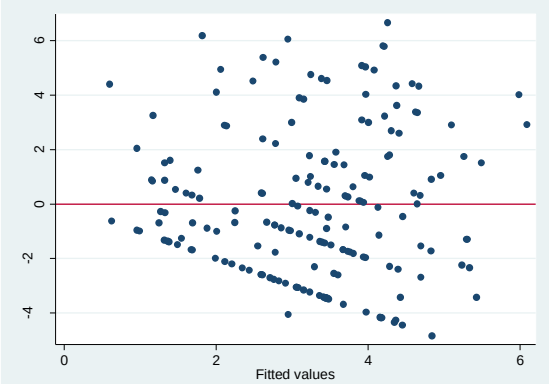


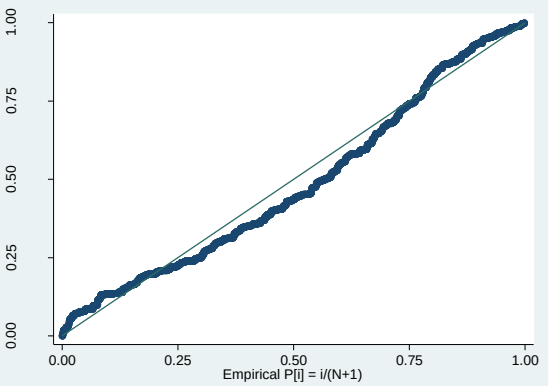
Imputation 4





Imputation 15





6.6 Discussion and summary

6.6.1 EQ-5D – health-related quality of life

All three datasets (START, SHIELD-CSP-RYCT and MODEM) analysed for this chapter, included the EQ-5D health-related quality of life measure at baseline and follow-up. Multiple regression analysis revealed some differing, but also some overlapping results. Carer age was found to be significantly associated with health-related quality of life at follow-up in the imputed START data. This association was not observed in the complete case analysis. The results suggested that older carers were more likely to experience lower health-related quality of life than younger carers at follow-up. No significant associations between EQ-5D and carer age were found in the analysis of SHIELD-CSP-RYCT or MODEM data.

In SHIELD-CSP-RYCT, on the other hand, female carers were found to be more likely to experience worse health-related quality of life at follow-up than the male carers in the study. No significant associations with respect to carer gender were found in the analysis of MODEM and START data. Statistically significant associations were also observed for the variable relationship to the care-recipient. In the START complete case analysis, the group other carers was found to be more likely to experience better health-related quality of life than spouses. No statistically significant difference could be observed between spouses and filial carers. The variable was not found to improve the model using imputed START data. In the analysis of SHIELD-CSP-RYCT, filial carers were found to be more likely to express better health-related quality of life than spouse carers. No significant association between relationship and health-related quality of life could be found in any of the MODEM models.

In the literature, very few studies were found that specifically focused on health-related quality of life of carers of people with dementia, which also investigated carer age and gender. With respect to carer gender, two cross-sectional studies reported significant differences in the health-related quality of life of male and female carers of people with dementia. In both, a Spanish study and a Canadian study focusing on spouse carers, male carers were found to score better on the physical health component of the measure. In the Canadian sample male carers were also found to score better on the mental health component, while no difference was observed in the Spanish sample (Gibbons et al., 2014;

Argimon et al., 2004). These findings are consistent with the findings of the SHIELD-CSP-RYCT model. On the other hand, three cross-sectional studies investigating the health-related quality of life of carers of people with dementia in Chile, Colombia and Canada, did not find gender differences (Aravena, Albala & Gitlin, 2018; Arango Lasprilla et al., 2009; Bell, Araki & Neumann, 2001).

Furthermore, the studies by Bell and colleagues (2001) and by Arango Lasprilla and others (2009) also did not find differences in health-related quality of life with respect to carer age. On the other hand, an English study, investigating EQ-5D as in this research, found that in comparison with non-carers, younger carers had lower EQ-5D scores, but carers aged 85 years and above had higher EQ-5D scores (Thomas et al., 2015). This study, however, did not specifically focus on carers of people with dementia.

The results from my research, which suggest that older carers experience worse health-related quality of life, in comparison with inconclusive findings from previous literature raise two issues. These are: carer age range and selection bias. First, as discussed in Chapter 4 and reported in other research, carers of people with dementia tend to be older than carers for people with other illnesses (Bartfay & Bartfay, 2013). This might lead to a narrow range of carer age. START, where some carers were sampled from a centre focusing on people with early onset dementia reflects a slightly wider carer age range in comparison to MODEM and SHIELD-CSP-RYCT (see Chapter 4, Table 4.1). Perhaps greater variation in carer age can explain differences in results between START, MODEM and SHIELD-CSP-RYCT models.

The finding from imputed START data that older carers experience worse quality of life sits well with results from a recent publication on general population health in England. Public Health England (2017a) reported an increase in rates of morbidity with age. People aged 80 years and older were found to have ‘twice the morbidity rate’ of people in the age group 60 to 64. Data from Somerset showed that in the population aged 60 and above approximately 50% live with two or more morbidities and around 25% live with at least three long-term conditions. Among people aged 80 and above, in the same population, nearly 90% lived with at least one long-term conditions and 44% lived with three or more (Public Health England, 2017a).

Second, a form of self-selection bias might exist among people providing unpaid care in old age. While carers of people with dementia, and particularly elderly spouses, are likely to become carers by default, their own health status has to allow them to provide the

necessary support. While many spouses will stretch their own abilities in order to support their partners with dementia, others will be too limited in their abilities to take up the role. A similar hypothesis was also suggested by Thomas and colleagues (2015).

Next, participation in research is a task that carers are only likely to agree to if they feel sufficiently in control of their situation (see Chapter 3.4.1). Perhaps this combination creates a situation where older carers participating in dementia research are disproportionately healthier than those who decline participation or are unable to provide care.

The finding from imputed SHIELD-CSP-RYCT data that women are likely to experience worse health-related quality of life is also supported by population health statistics. While women continue to have longer life expectancy than men, women also spend more time in poor health. In England, women can expect to live 3.6 years longer than men, but can only expect to spend 0.7 years of this longer life expectancy in good health. This means that women, on average, spend a greater proportion of their later life in poor health (data from 2013 to 2015) (Public Health England, 2017a). Older carers of people with dementia predominantly are spouses who gradually grow into caring for their partner. Findings from the qualitative study (Chapter 5) showed that, unless physical illness caused the carer to be bedbound, carers took on responsibilities for their relative with dementia despite their own health issues. These patterns were also reported in the literature (Conde-Sala et al., 2010; Friedemann & Buckwalter, 2014; Pöysti et al., 2012). The finding that carers frequently place the need of their care-recipient above their own might put their personal health additionally at risk (Brodaty & Aggar, 2017).

The findings that filial carers and other carers experienced better health-related quality of life than spouses also fit with these observations. Serrano-Aguilar, Lopez-Bastida and Yanes-Lopez (2006) also found that filial carers experienced greater health-related quality of life than spouse carers. Filial carers tend to be younger than spouse carers and therefore are more likely to be in better health. Similarly, carers other than the partner or child of the person with dementia are likely to only take on care responsibility if they are in a position to do so. On the other hand, given the increase in comorbidities reported by Public Health England (2017a), it might be that the oldest carers are comparatively healthier than their peers if they are able to continue providing care.

Such a pattern would also explain the increase in health-related quality of life among the oldest old discussed earlier (Thomas et al., 2015). Furthermore, patterns of

institutionalisation, where people with dementia having a partner were found to be less likely to move into residential care, also point into a similar direction (Knapp et al., 2016). However, in comparison to the general population, the literature uniformly reported lower health-related quality of life for carers of people with dementia (Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006; Arango-Lasprilla et al., 2010; Välimäki et al., 2016).

In Section 6.2 it was pointed out that only very small, non-significant differences in the outcome variable EQ-5D over the course of one year could be observed. Välimäki and colleagues (2016), who investigated health-related quality of life over time in Finland, found similar results. A significant deterioration of the index score used could only be observed in year three. Similarly, Yikilkan and colleagues (2014) reported an impact on carers' general health among those caring for more than two years. This could mean that carers' health-related quality of life does not vary substantially over relatively short periods of time, but the effect of caring might show over a longer period. For MODEM data only 12 months follow-up data were available. As most carers spend considerable time supporting a relative with dementia, it would be important if more studies were able to examine health-related quality of life over time.

Finally, two studies pointed out that while the EQ-5D assesses health-related quality of life, caution should be exercised when attempting to interpret the measure for purposes of carers' *overall* quality of life as it was found not to be 'particularly effective for capturing the true impact on caregivers' due to its focus on physical health (Reed et al., 2017, p.22; Dow et al., 2018).

6.6.2 HADS depression & GHQ – the relevance of mental health in the well-being discourse

Chapter 2 highlighted the importance of mental health to carers' well-being and quality of life. In this analysis, two scores commonly used to measure mental health were analysed to see whether differences over time were associated with carer gender and age could be observed over time. No significant associations with carer age or gender could be observed in the HADS analysis of START, but the same outcome measure analysed using SHIELD-CSP-RYCT data showed that older carers were less likely to experience symptoms of depression at follow-up. An association with carer age was also found in the MODEM complete case analysis of GHQ. The interpretation of the MODEM results contradicted the SHIELD-CSP-RYCT findings by suggesting that older carers were more likely to have lower psychological health. However, this result was lost following imputation.

The variable relationship to the care-recipient was significantly associated with HADS depression score at follow-up in both the analysis of SHIELD data and complete case analysis of START data. In the SHIELD-CSP-RYCT analysis the significant negative association with both filial carer and other carers suggests that spouse carers were more likely to experience depressive symptoms than filial or other carers at follow-up. Similarly, in the START complete case analysis, spouses were found to experience worse mental health than other carers. However, there was no significant difference in the experience of depression between spouses and filial carers. The variable 'relationship to the care-recipient' was not included in the model using imputed data.

One of the personal well-being questions explored in MODEM (PWB4) also focused on mental health. It asked carers to rate 'On a scale, where nought is 'not at all anxious' and 10 is 'completely anxious', overall, how anxious did you feel yesterday?' Results from the complete case analysis suggested that older carers were more anxious, but this relationship lost its significance in the analysis using imputed data.

Contrary to results from this study, where none of the models showed a statistically significant difference between the mental health of men and women, previous studies overwhelmingly report that women providing care to people with dementia to experience more symptoms of depression, anxiety and worse overall mental health scores than men (Andreakou et al., 2016; Borsje et al., 2016; Fauth, Femia & Zarit, 2016; Gibbons et al., 2014; Lethin et al., 2017; Orgeta & Lo Sterzo, 2013; Bookwala & Schulz, 2000; Borden & Berlin, 1990; Meshefedjian et al., 1998; Pinquart & Sörensen, 2006; Schoenmakers, Buntinx & DeLepeleire, 2010b; Tommis et al., 2007). Pinquart and Sörensen (2006) in their meta-analysis reflected on the possibility that women may more readily disclose negative feelings and health problems than men.

In the literature, only two other studies could be identified that also did not observe gender differences in carer depression (Pöysti et al., 2012; Arango Lasprilla et al., 2009). The results of this research, while somewhat inconsistent with the majority of findings in the literature, sit well with findings from the qualitative study (Chapter 5). There men and women alike reported experiencing mental health issues. Some had experienced symptoms of depression and/or anxiety before, while others reported having become anxious or depressed while caring for their relative with dementia. It was interesting to find that some men reported externalising behaviour, such as seeking a diagnosis after family reporting snappy, uptight behaviour or experiencing painful tension in their leg. The expression of

externalising symptoms of depression is consistent with a body of literature that focuses on 'masculine' symptoms of depression, such as anger attacks, aggression, substance use, risk taking and hyperactivity (Martin, Neighbors & Griffith, 2013). Martin, Neighbors and Griffith (2013) found that when including externalising symptoms of depression, the gender difference between men and women disappeared. In this study, however, neither the outcome measure HADS depression measure nor the General Health questionnaire included such externalising factors.

Perhaps the absence of a statistically significant difference was linked to the fact that all carers in the more intensive part of this study (Chapter 5) voluntarily agreed to participate after being informed about the nature of the studies. This means that there might be a bias in men and women who were prepared to participate in trials testing interventions to support carers (SHIELD-CSP-RYCT; START) and those who agreed to participate in the MODEM cohort study. As described in Chapter 5.3.1, several husbands started lobbying systematically for their needs or engaged with research. This agenda-setting, particularly observed among husbands, might reflect that men identifying with their carer role and participating in research were more open to report on their mental health.

In contrast to carer gender, the variable carer age was much less frequently discussed in the literature. Among five studies investigating associations between depressive symptoms and carer age, only one study found a significant relationship (Liang et al., 2016; Leggett et al., 2015; Arango Lasprilla et al., 2009; Schoenmakers, Buntinx & DeLepeleire, 2010b; Au et al., 2009). Liang and colleagues (2016), who looked at a Chinese sample, reported carer age and depressive symptoms to be positively associated. This is consistent with analysis of the Survey of Health, Ageing and Retirement in Europe investigating a sample of family carers aged 50 and older, which showed that the association between provision of personal care and poor mental health strengthened with increasing carer age (Hiel et al., 2015, p.66). Similarly, a study investigating factors associated with depression among older carers found significant associations with greater hours spent caring and higher levels of neuroticism (Loi et al., 2016). The model using MODEM complete case data supported this finding. However, contrasting results were found using the SHIELD-CSP-RYCT model, which suggested that older carers experienced fewer symptoms of depression.

The variable relationship, again, presented a clearer and more coherent picture. Consistent with results from the analysis of SHIELD-CSP-RYCT and the START case

study, several studies reported spouses to be associated with greater psychological distress than filial carers or other carer groups (Borsje et al., 2016; Ask et al., 2014; Lethin et al., 2017; Rosness, Mjørud & Engedal, 2011; Covinsky et al., 2003; Schoenmakers, Buntinx & DeLepeleire, 2010b). The consistency of these findings in contrast to the scarcity of evidence on the relationship between carer depression and carer age require some further thought. Spouses of people with dementia tend to be slightly older than filial carers. However, the difference may be small. The comparison of relationship to the care-recipient by age group in Chapter 4 showed that, especially in the younger age band (carers aged 50 to 75), there were substantial proportions of both spouse and filial carers. The overwhelming absence of significant findings in the literature and the contradictory findings from this analysis with respect to carer age and depression suggest that perhaps underlying relationship components rather than age may affect carers' mental health.

Fauth and colleagues (2012) explored the concept of relationship closeness and its influence on carer psychological well-being and physical health. The study presented a rather complex picture. It found that greater relationship closeness at baseline was associated with better mental health scores at baseline, but also predicted 'significant decreases […] over time'. However, using a depression measure the effect over time was no longer observed. The study found that carers with greater relationship closeness at baseline showed significantly fewer symptoms of depression at baseline, but closeness was not associated with a change in depressive symptoms over time (Fauth et al., 2012, p.704). These findings suggest that relationship quality might play an underlying role. In my qualitative study (Chapter 5) several spouses reported that they could no longer consider their care-recipients as their partners. This was also found in other research (Winter, Gitlin & Dennis, 2011). Where, however, the spouse with dementia was able to appreciate the support received, this positively contributed to spouses' mental health. Monin, Schulz and Feeney (2015) reported similar findings. The loss of companionship, together with a narrowing social life that many spouses experience might explain why spouses experience more symptoms of depression than filial carers or other family members and friends. Filial carers and other carers might be able to mitigate better against these effects through the presence of their own partners, family and friends. Most filial carers in the qualitative study reported receiving moral and practical support from their spouses and other family members.

As with studies investigating carer health-related quality of life, there have been few studies investigating carer well-being over time. Only one study explored the time component by including the years spent caring in the analysis. The study found that carers who provided care for three or more years experienced 'an even higher incidence of anxiety' (Yikilkan, Aypak, & Görpelioğu, 2014, p.194).

6.6.3 Happiness and personal growth – results from hedonic and eudaimonic well-being questions

Besides the commonly used quality of life measure EQ-5D and mental health measures HADS and GHQ, this thesis also explored measures collecting information on carer happiness, personal growth, life satisfaction and the feeling that life is worthwhile, as these fall under the umbrella of hedonic and eudaimonic well-being (see Chapter 2).

Happiness, for instance, was measured using question 12 of the HSQ questionnaire collected in START 'Have you been a happy person?' No statistically significant difference could be observed for the variables carer age and carer gender or relationship to the care-recipient in any of the models explored. One of the personal well-being questions (PWB3) in MODEM also explored carer happiness with the question 'Overall, how happy did you feel yesterday?' A significant relationship between carer gender and happiness at follow-up in the complete case analysis suggested that female carers were less likely to rate high on happiness than male carers. This significant relationship disappeared following imputation. No previous studies could be identified that focused on the happiness of carers of people with dementia. The lack of such studies might be linked to the somewhat narrow concept of carer well-being, which, as discussed in Chapter 2, predominantly focuses on aspects of physical and mental health.

Personal growth was measured using the PGI, collected as part of SHIELD-CSP-RYCT. Analysis of this measure did not find any significant association with carer gender, age or relationship to the care-recipient. The related concept of feeling that 'Overall, to what extent do you feel that the things you do in your life are worthwhile?' was measured as part of the MODEM personal well-being questions (PWB2). As with the analysis of the PGI, no statistically significant differences could be observed with respect to carer age and gender or relationship to the person with dementia.

In contrast to the many studies reporting on carer quality of life and mental health, only four studies could be identified fitting under the terms personal growth and meaning derived from caring. Consistent with the results of this study, the German sample did not

show significantly different associations between carer age, gender or relationship and personal growth. Instead its results indicate that personal growth is associated with an increase in number of care tasks (Leipold, Schacke & Zank, 2008). The second study, using an American sample, did not reflect on carer age or gender in its final analysis; however, it found that adult children experienced more personal growth than spouses of people with Alzheimer's disease (Ott, Sanders & Kelber, 2007). The question of what predicts the experience of meaning among carers of people with dementia was investigated in an English study. Carer age and gender were not specifically reported, but the cross-sectional study found that spouse carers, those spending more hours on care and those with greater religiosity found the greatest meaning in their care responsibility (Quinn, Clare & Woods, 2012). The related concept of self-esteem was investigated in a non-dementia-specific Canadian carer sample. This study found that daughters, despite experiencing the greatest burden from caring, also report highest self-esteem. Wives, in contrast, reported lower self-esteem than daughters, sons or husbands (Chappell, Dujela & Smith, 2015).

Personal well-being question one explored the concept of life satisfaction. The statistically significant association between life satisfaction and carer gender, indicating that women were less likely to experience life satisfaction than men, observed in the complete case analysis was lost in the analysis using imputed data. As with the concepts of personal growth and meaning, only a few studies could be identified focusing on life satisfaction of carers of people with dementia; these used samples from Scandinavia, the US and Australia. McConaghy and Caltabiano (2005) in their Australian, cross-sectional sample did not find differences in the rating of life satisfaction between male and female carers or between older and younger carers. Holst and Edberg (2011), who analysed carer satisfaction using the question 'How often do you feel satisfied with the role as a caregiver?' over the course of three years, found that male respondents more frequently reported satisfaction with their role as a carer than female respondents, both, after one and after 3 years. Similar results were found in the American sample, emphasising again the link between life satisfaction and mental health, where women with greater symptoms of depression reported lower levels of life satisfaction (Taylor et al., 2008, p.326). Findings from the qualitative study, presented in Chapter 5, support these findings, showing that women felt more limited in pursuing their own interests than men while caring for their spouses with dementia.

Even though no statistically significant difference could be found with respect to carer age, evidence from the literature has suggested that, in a general population, life satisfaction 'exhibits a U-shape function over the life course, with a low point at about the age of 50' (Helliwell, Huang & Wang, 2017, p.35; Schwandt, 2013; Blanchflower & Oswald, 2008; Stone et al., 2010; Van Landeghem, 2012; Weiss et al., 2012; Frey & Stutzer, 2002). Frey and Stutzer (2002) proposed that people felt unmet aspirations more strongly during midlife, but abandoned those as they became older (Schwandt, 2013, p.2). A similar explanation was put forward by Brassen and colleagues (2012). Their paper suggested lower 'emotional reaction to missed chances' with growing age (Schwandt, 2013, p.2). Furthermore, while researchers investigating life satisfaction found an overall U-shape function between the ages 20 and 70, they also showed a second decline among people aged 75 and over (Schwandt, 2013, p.3). In this thesis, the majority of carers were aged between 55 and 80 years (see Chapter 4). The relatively small age range covered includes both age ranges during which lower life satisfaction is experienced. In addition to this phenomenon observed in the general population, participants in the studies analysed here carry the responsibility for a person with dementia, which might further limit their ability to pursue personal aspirations. These factors might contribute to narrowing differences in life satisfaction among unpaid carers studied in this thesis.

Like carer age, relationship between carer and care-recipient did not improve the model of carer life satisfaction and was therefore not included in the complete case or imputed model. The model investigating purely carer and care-recipient characteristics (presented in Appendix 5.5) also did not show statistically significant differences by relationship for both complete case and imputed analysis. Only one previous study explored the association between the relationship of the care dyad and carer life satisfaction. In comparison to non-carers, co-resident spouses of people with dementia were found to experience 'moderately lower levels of life satisfaction' (Ask et al., 2014, p.413). The study reported a close link between life satisfaction and mental health, emphasising that spouses of people with dementia do not just report lower life satisfaction but also more symptoms of depression and anxiety.

The somewhat inconclusive results from this research and the limited evidence available from previous research uncovered in the literature review make it difficult to draw conclusions about patterns in carer happiness, personal growth and life satisfaction of carers of people with dementia. Women and spouses, as found in the literature (and to some

extent in this thesis) appear to be more vulnerable. However, more work needs to be done to explore why women indicate the experience of more symptoms of depression and anxiety and lower ratings of happiness and life satisfaction.

6.6.4 Limitations

As outlined in Table 6.2.3, the variables used to estimate carer well-being and quality of life over the period of one year showed little variation in means. Calculation of sample size based on a pre-determined, clinically significant effect size between groups, such as between male and female carers or between baseline and one-year follow-up, could have ensured that the sample was large enough for effects to be detected (Sullivan & Feinn, 2012). Not conducting these assessments of statistical power means that the analysis is at risk of a Type II error; i.e. that statistical analysis of the data may have suggested that there was no difference in well-being and quality of life outcomes over time when in fact there was such a difference (Biau, Kernéis & Porcher, 2008). Guidance states that statistical power should be determined prior to starting a study, but in this case secondary data were analysed, which made it impossible to increase sample size.

Post-hoc analysis comparing the observed effect size for the different outcome variables by carer gender to the effect size necessary to have observed a statistically significant difference for carer gender for each of the outcome variables, given the sample sizes in each dataset, showed that some of the models were at risk of Type II error. Only the START and SHIELD-CSP-RYCT models using EQ-5D as an outcome measure and the START model for HADS depression were found to have observed effect sizes for carer gender larger than the calculated necessary effect size (see Table 6.6.4).

Table 6.6.4 Overview of available and necessary effect size to detect carer gender difference for each of the outcome variables considered

	Observed effect size	Calculated necessary effect size
START		
EQ-5D	0.277	0.113
HADS depression	0.274	1.898
HSQ12	0.437	0.566
MODEM		
EQ-5D	0.04	0.081
GHQ12	0.37	1.243
PWB1	0.232	0.703
PWB2	0.235	0.729
PWB3	0.222	0.831
PWB4	0.047	1.134
SHIELD-CSP-RYCT		
EQ5D	0.349	0.119
HADS depression	0.047	1.744
PGI	0.129	0.863

Chapter 7

What factors influence the time commitment of different tasks by men and women of different age groups caring for a relative with dementia?

Care commitment was shown to influence carers' well-being and quality of life (see Chapters 5 and 6; Joling et al., 2015; Chappell & Reid, 2002; Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006). This chapter provides more detailed insights into the composition of care tasks that family carers take up when supporting a relative with dementia. This was explored with the help of an amended version of the Resource Utilization in Dementia (RUD) questionnaire, which was adapted for this research. This chapter first provides a descriptive overview of the different care tasks investigated by carer group. Second, results are presented from cross-sectional multiple regression analyses using negative binomial models. These models investigated factors that influence the time spent by carers of people with dementia on care tasks grouped into ADL and IADL tasks, supervision and total care. A particular focus is placed on differences between male and female carers, carers of different ages and in different relationships to the care-recipient.

7.1 Time commitment to care

Across the literature it has been acknowledged that unpaid carers carry the greatest responsibility when it comes to the provision of dementia care (Wimo et al., 2013c; Michalowsky et al., 2016). The time carers spend providing care has long been recognised as an important unit of information when trying to understand who provides dementia care. Furthermore, measures collecting information on the time carers spend are traditionally used to inform the cost of unpaid care. Knapp and colleagues, for instance, estimated that the total societal cost of dementia in the UK was £26.3 billion. The costs of unpaid care, based on the time carers reported to spend caring, was found to amount to approximately 44.1% (£11.6 billion) of the total costs (see Prince et al., 2014). Others have estimated the proportion of unpaid care to total cost of care to exceed 50% (Dodel et al., 2015).

Only in a limited numbers of studies, however, were these time measures used to investigate factors influencing the time carers spent on dementia care or indeed whether there were differences by care tasks (e.g.Wimo et al., 2002). While there is evidence from the literature suggesting that male carers, and sons in particular, provide less personal care,

little information is available regarding variables influencing the time carers commit to caring for a person with dementia in the community (ONS, 2013a; Sharma, Chakrabati & Grover, 2016; Pinquart & Sörensen, 2006). A better understanding of aspects driving care time commitment, however, could be relevant to inform policy efforts to better support carers looking after their relatives with dementia. To shed light on these issues this chapter will investigate '*What factors influence the time committed to caring for a person with dementia? And do men and women and carers of different ages differ in the time they spend caring?'* Independent variables explored in this chapter were selected based on the theoretical framework outlined in Chapter 2.5.

7.2 Descriptive analysis

As described in Chapter 3.6, in this chapter I present data from 244 carers looking after a person with dementia in the community and who responded to the amended RUD questionnaire developed for this thesis. Detailed description on how the questionnaire was developed can be found in Chapter 3.6.1. For this study, carers responded to very detailed questions on how much time they spent on an average day on tasks grouped into the categories ADLs, IADLs, supervision and total care. An overview of the ADL and IADL sub-categories investigated in this chapter can be found in Table 7.2.1.

Table 7.2.1 Overview of sub-categories of Activities of Daily Living and Instrumental Activities of Daily Living

Activities of Daily Living	**Instrumental Activities of Daily Living**
Personal hygiene	Preparing food
Using the toilet	Doing routine housework and laundry
Dressing or undressing	Transportation
Eating including cutting up food	Helping with finances
Getting around indoors	Shopping for food
Getting around outside the house	Taking (and preparing) medication

The majority of unpaid carers in this study were wives (46.3%), husbands (27.9%), daughters (16.4%) and sons (5.3%). Some carers in the dataset came from the care recipients' wider family, including brothers and sisters (n=2), family members (n=3), friends (n=2) and others (n=3). This group of carers made up 4.1% of the sample. This grouping of wider family carers was not included in the analysis presented in this chapter. All but one of the carers falling into the category 'other' were women. An overview of the

tasks in which the different carer groups engaged and the time that was spent on each of the tasks can be found in Table 7.2.2.

The largest proportion of carers involved in ADL and IADL activities were husbands and wives caring for their spouse with dementia. Approximately 41% of spouses provided support with personal hygiene, compared to about 35% of filial carers. A smaller proportion of carers supported their care-recipients with toileting. On average, daughters and husbands provided the greatest amount of time. Nearly half of wives (48.7%) and husbands (47.1%) supported their partners with dressing. But also 45% of daughters and 38% of sons provided such support. Proportionately fewer wives (11.5%) than husbands (29.4%) and daughters (25%) stated that they supported their care-recipient with eating. Sons (53%) and daughters (57%), in comparison, were found to be slightly more engaged in helping their parents with getting around outdoors (spouses 46.5%).

When looking at the proportion of carers involved with IADL tasks, it became evident that most of the husbands, closely followed by wives, supported their spouses with the preparation of food, housework, transportation, finances and shopping for food. Only a larger proportion of wives provided support with 'taking and preparing medication' (84.1%). Proportionately fewer sons than spouses or daughters were involved in IADL tasks such as preparing food, transportation, shopping or preparing medication. Sons also spent less time on the different tasks. As with ADL activities, the proportion of daughters involved in the different activities was similar to that of spouses providing dementia care.

Respondents falling into the category 'other carers' provided most support with helping the person with dementia getting around inside and outside the house and with IADL tasks, such as helping with finances and shopping. These findings were also reflected in the aggregated time that unpaid carers spent on ADL, IADL, supervision and total time caring (Table 7.2.4). Husbands, wives and daughters on average spent more hours on ADL and IADL tasks than sons and other carers. While the difference in the provision of personal care tasks between the three dominant groups was relatively small, a greater difference in mean time spent caring could be found for IADL tasks and supervision. For these tasks' spouses provided more hours.

In some care situations, family carers received help and support when looking after their spouse or parent with dementia. When looking at the number of carers receiving support from paid carers, other unpaid carers or a combination of the two it becomes evident that proportionately more spouses than filial carers received unpaid care support

with ADL tasks (Table 7.2.5). None of the carer groups received paid support for help with eating, transportation and finances. However, for some IADL tasks such as housework, transportation, finance and shopping as well as for the ADL task moving around outdoors comparable proportions of spouses and filial carers received additional unpaid support. Furthermore, a greater proportion of filial carers than spouses were found to receive support from both other unpaid and paid carers. When comparing spouses, proportionately more husbands received formal support with personal care tasks than wives. This might in part be because a larger proportion of husbands in this sample cared for wives with more advanced dementia (Table 7.2.3).

Table 7.2.2 Time carers spent on specific care tasks

	Husbands		Wives		Sons		Daughters		Others	
	N	Mean (StdDev)	N	Mean (StdDev)	N	Mean (StdDev)	N	Mean (StdDev)	N	Mean (StdDev)
Activities of daily living										
Personal hygiene	28	32.3 (29.9)	47	50.30 (75.21)	5	32 (30.9)	14	39.9 (44.1)	1	40
Toileting	16	44.5 (32.1)	20	37.68 (32.34)	3	11.4 (16.1)	8	63.9 (68.1)	1	45
Dressing	32	22.6 (18.8)	55	25.61 (22.91)	5	16.2 (14.9)	18	26.8 (31.9)	3	13.3 (15.3)
Eating	20	33.1 (29.0)	13	23.31 (27.38)	1	120	10	17.9 (23.6)	2	52.5 (53.0)
Indoors	19	32.8 (34.4)	12	41.25 (40.85)	2	12.5 (3.5)	8	45.9 (40.7)	5	10.5 (16.9)
Outdoors	32	62.4 (53.2)	53	72.76 (79.49)	7	31.9 (52.5)	23	47.9 (52.5)	5	11.5 (4.9)
Instrumental activities of daily living										
Preparing food	48	79.8 (41.8)	74	90.5 (437)	8	44.9 (20.7)	27	64.6 (42.7)	3	130 (96.4)
Housework	48	53.8 (40.4)	71	79.7 (53.9)	9	39.8 (27.8)	28	80.4 (61.7)	7	54.9 (85.6)
Transportation	42	47.8 (44.4)	60	57.5 (48.8)	10	17.6 (17.7)	31	28.8 (35.3)	4	24.5 (25.4)
Finances	49	15.4 (17.4)	74	25.9 (40.3)	9	7.1 (8.8)	32	10.7 (10.9)	9	7.3 (4.8)
Shopping	56	31.1 (41.9)	88	25.5 (19.6)	10	13.9 (8.2)	34	19.9 (13.8)	9	13.5 (14.7)
Medication	51	11.9 (15.8)	95	12.8 (12.9)	6	5.5 (5.9)	31	9.5 (8.3)	5	8.1 (2.6)

Table 7.2.3 Dementia severity by carer group

	Husbands	Wives	Sons	Daughters	Others
Mild	26 (38.2%)	55 (48.7%)	4 (30.8%)	17 (42.5%)	2 (20.0%)
Moderate	15 (22.1%)	41 (36.3%)	4 (30.8%)	16 (40.0%)	5 (50.0%)
Severe	27 (39.7%)	17 (15.0%)	5 (38.5%)	7 (17.5%)	3 (30.0%)

Table 7.2.4 Time unpaid carers spent on different tasks

	Observations	Mean	Std. Dev.	Min	Max
ADL scores					
ADL total	244	1.3	1.8	0	9.2
ADL husbands	68	1.4	1.9	0	7.7
ADL wives	113	1.4	1.7	0	8.7
ADL sons	13	0.8	1.5	0	4.4
ADL daughters	40	1.3	2.1	0	9.2
ADL others	10	0.6	1.3	0	4.3
IADL scores					
IADL total	244	2.8	2.3	0	12.4
IADL husbands	68	2.8	2.3	0	8.3
IADL wives	113	3.1	2.3	0	124
IADL sons	13	1.5	1.2	0	3.5
IADL daughters	40	2.6	2.2	0	8.2
IADL others	10	1.8	2.7	0	9.9
Supervision all unpaid carers					
Supervision all unpaid carers	244	10.5	9.6	0	48
Supervision husbands & all unpaid carers	68	11.3	8.8	0	29.7
Supervision wives & all unpaid carers	113	12.2	9.8	0	29
Supervision sons & all unpaid carers	13	9.6	14.0	0	48
Supervision daughters & all unpaid carers	40	6.2	7.5	0	24
Supervision others & all unpaid carers	10	4.7	5.6	0	15.5
Supervision only interviewed carer					
Supervision total	224	10.6	8.9	0	24
Supervision husbands	62	11.7	8.2	0	24
Supervision wives	103	12.9	9.2	0	24
Supervision sons	13	7.5	9.4	0	24
Supervision daughters	37	5.0	6.6	0	24
Supervision others	9	4.5	5.1	0	13
Total time spent caring					
Total time	244	14.6	11.4	0	48.7
Total time husbands	68	15.5	10.1	0	34.1
Total time wives	113	16.7	11.6	0	40.3
Total time sons	13	11.8	14.8	0	48.7
Total time daughters	40	10.2	10.1	0	36.2
Total time others	10	7.1	9.1	0.2	28.8

Table 7.2.5 Support family carers received

	Husband	Wife	Son	Daughter	Other
Activities of daily living					
Personal hygiene					
Formal	6 (8.8%)	1 (0.9%)	1 (7.7%)	7 (17.5%)	1 (10.0%)
Unpaid	21 (30.9%)	41 (36.3%)	2 (15.4%)	7 (17.5%)	1 (10.0%)
Both	7 (10.3%)	7 (6.2%)	3 (23.1%)	7 (17.5%)	
Toileting					
Formal	2 (2.9%)			2 (5.0%)	1 (10.0%)
Unpaid	9 (13.2%)	18 (15.9%)	1 (7.7%)	4 (10.0%)	1 (10.0%)
Both	8 (11.8%)	3 (2.7%)	2 (15.4%)	5 (12.5%)	
Dressing					
Formal	3 (4.4%)			5 (12.5%)	2 (20.0%)
Unpaid	23 (33.8%)	49 (43.4%)	1 (7.7%)	13 (54.2%)	3 (30.0%)
Both	9 (13.2%)	7 (6.2%)	4 (30.8%)	6 (25.0%)	
Eating					
Formal					1 (10.0%)
Unpaid	17 (25.0%)	11 (9.7%)		6 (54.6%)	2 (20.0%)
Both	3 (4.4%)	2 (1.8%)	1 (7.7%)	5 (12.5%)	
Indoors					
Formal				1 (2.5%)	
Unpaid	16 (23.5%)	10 (8.9%)		7 (17.5%)	4 (40.0%)
Both	7 (10.3%)	3 (2.7%)	2 (15.4%)	1 (2.5%)	1 (10.0%)
Outdoors					
Formal	1 (1.5%)			2 (5.0%)	
Unpaid	32 (47.1%)	55 (48.7%)	6 (46.2%)	20 (50.0%)	6 (60.0%)
Both	3 (4.4%)	9 (7.9%)	1 (7.7%)	4 (10.0%)	
Instrumental activities of daily living					
Preparing food					
Formal	1 (1.5%)		2 (15.4%)	2 (5.0%)	2 (20.0%)
Unpaid	43 (63.2%)	75 (66.4%)	5 (38.5%)	20 (50.0%)	4 (40.0%)
Both	6 (8.8%)	2 (1.8%)	3 (23.1%)	7 (17.5%)	
Housework					
Formal	1 (1.5%)	3 (2.7%)	2 (15.4%)	7 (17.5%)	2 (20.0%)
Unpaid	33 (48.5%)	59 (52.2%)	6 (46.2%)	20 (50.0%)	6 (60.0%)
Both	16 (23.5%)	15 (13.3%)	3 (23.1%)	8 (20.0%)	1 (10.0%)
Transportation					
Formal					
Unpaid	42 (61.8%)	69 (61.1%)	7 (53.9%)	25 (62.5%)	4 (40.0%)
Both	6 (8.8%)	8 (7.1%)	3 (23.1%)	8 (20.0%)	1 (10.0%)
Finances					
Formal					
Unpaid	53 (77.9%)	88 (77.9%)	11 (84.6%)	34 (85.0%)	9 (90.0%)
Both		1 (0.9%)		3 (8.1%)	
Shopping					
Formal				3 (7.5%)	
Unpaid	56 (82.4%)	88 (77.9%)	9 (69.2%)	32 (80.0%)	7 (70.0%)
Both	1 (1.5%)	3 (2.7%)	1 (7.7%)	2 (5.0%)	2 (20.0%)
Medication					
Formal			3 (23.1%)	3 (7.5%)	2 (20.0%)
Unpaid	48 (70.6%)	94 (83.2%)	6 (46.2%)	21 (52.5%)	5 (50.0%)
Both	4 (5.9%)	2 (1.8%)	2 (15.4%)	10 (3%)	
Total number of carers	68	113	13	40	10

*see Table 7.2.5 by severity in Appendix 9

7.3 Univariate analyses for time spent on ADL, IADL and supervision

Univariate negative binomial regression analyses of the cross-sectional data were performed on the five outcome variables time spent on ADLs, IADLs, supervision by all carers, supervision by the unpaid interviewed carer and on total time spent caring. The aim was to explore the associations with each of the independent variables taken into consideration based on the framework presented in Chapter 2.

The variable carer gender showed no significant relationship with any of the outcome variables. For carer age, a significant association was only found with the variable supervision by the interviewed unpaid carer. The variable relationship to the care-recipient, was significantly associated with time spent on IADL tasks, both variables investigating time spent on supervision and total time spent caring. That is, filial carers spent significantly less time on IADL tasks, supervision and overall care than spouses. The group 'other carers' also spent significantly less time on both supervision measures and time spent on total care as compared to spouse carers. The variable co-residence was the only variable that had a statistically significant association with all five outcome variables. In addition, carer employment status, the experience of sleep-disruption due to care needs, dementia severity and the experience of challenging behaviour by the person with dementia (NPI) showed statistically significant associations with several of the five outcome measures.

Table 7.2.1 provides an overview of the estimated coefficients for each of the univariate regressions and whether they reached statistical significance. Statistically significant associations of these univariate analyses with the outcome variables were used as indicators for variables to be introduced in respective negative binomial regression models presented in this chapter.

Table 7.3.1 Univariate negative binomial regression models for time spent on ADL, IADL and supervision

Variables	**Time spent on ADL by all unpaid carers**		**Time spent on IADL by all unpaid carers**		**Time spent on supervision by all unpaid carers**		**Time spent on Supervision by interviewed carer**		**Total time spent on all care activities by all unpaid carers**	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	244		244		244		224		244	
Female		0.0275		0.1277		-0.0507		-0.0327		-0.0104
Carer age	242	-0.0048	242	0.0053	242	0.0116*	222	0.0227***	242	0.0091*
Relationship	244		244		244		224		244	
Filial carer		-0.1199		-0.2667**		-0.5187***		-0.7878***		-0.4286***
Other unpaid		-0.8786		-0.4960		-0.9266**		-1.0258***		-0.8277**
Carer education	244		244		244		224		244	
Further education		-0.1278		-0.0649		0.0008		-0.0531		-0.0217
Higher education		0.1167		-0.1776		-0.2209		-0.2515		-0.1807
Other		0.2584		-0.1061		-0.1124		-0.1649		-0.0757
Carer employment	244		244		244		224		244	
Not working		0.3115		0.3247**		0.4396**		0.6944***		0.4052***
Co-residence	244		244		244		224		244	
Yes		0.5377**		0.7328***		0.9509***		1.4415***		0.8644***
Carer sleep-disruption	244		244		244		224		244	
Yes		0.9178***		0.4818***		0.2726*		0.2357*		0.3665***
Carer OARS rating	234		234		234		215		234	
Mildly and moderately impaired social resources		0.0737		0.2810*		0.0226		0.0049		0.074
Severely and totally impaired social resources		0.2408		0.3804**		0.1254		0.1205		0.1821
GHQ	240	0.0081	240	0.0342**	240	-0.0041	221	-0.0079	240	0.0049
Carer health	242		242		242		223		242	
Good		0.3449		0.1996		0.0253		0.0131		0.0856
Poor and very poor		0.0523		0.2766		0.1489		0.1949		0.1655
Carer chronic illness	244		244		244		224		244	
No		-0.0176		0.0559		-0.0529		-0.1265		-0.0292
Carer health problems due to caring	242		242		242		223		242	
No		-0.4841**		-0.5575***		-0.1046		0.0237		-0.2156

Variables	Time spent on ADL by all unpaid carers		Time spent on IADL by all unpaid carers		Time spent on supervision by all unpaid carers		Time spent on Supervision by interviewed carer		Total time spent on all care activities by all unpaid carers	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer receipt of counselling	244	-0.5025	244	-0.0877	244	-0.4193	224	-0.4031	244	-03704
Carer use community services	244		244		244		224		244	
Yes		0.3299*		0.2058*		0.2447		0.1447		0.2448*
Number of other care-recipients	243	0.0520	243	0.0171	243	-0.0191	223	-0.0288	243	0.0006
Age care-recipient	244	-0.0166	244	-0.0056	244	-0.0089	224	-0.0040	244	-0.0090
Gender care-recipient	244		244		244		224		244	
Female		0.0725		-0.1122		-0.1416		-0.2500*		-0.1168
Dementia severity	244		244		244		224		244	
Moderate		0.8252***		0.2551**		0.3196*		0.1790		0.3454**
Severe		1.2296***		0.5893***		0.4889**		0.2899*		0.5703***
Challenging behaviour care-recipient (NPI)	230	0.0172***	230	0.0115***	230	0.0103*	213	0.0050	230	0.0114**
BADL score	244	0.0649***	244	0.0297***	244	0.0282***	224	0.0191**	244	0.0333***
Hospital use care-recipient	244		244		244		224		244	
Yes		-0.2746		0.0471		-0.1863		-0.1452		-0.1509
Community medical care use C-R	244		244		244		224		244	
Yes		0.1536		0.2542		0.6979**		0.6102**		0.5417**
Day care use care-recipient	244		244		244		224		244	
Yes		0.4142**		0.2075*		0.2399		0.1569		0.2489**
Care provision by other carers	236		236		236		224		236	
Formal		0.3346		-0.1715		0.0104		0.0273		0.0060
Unpaid		0.2303		0.0862		0.2674		0.1284		0.2297
Both		0.5039**		0.0483		0.0716		-0.1407		0.1085
Research assistants	244		244		244		224		244	
CB		0.6166*		0.4571**		0.0614		-0.1103		0.1738
SB		0.2573		0.3647*		0.3224		0.2599		0.3248
RH		0.4278		0.3633		0.3119		0.2408		0.3299
EB		0.2191		0.4148*		0.0494		-0.1598		0.1330
MC		0.7405		0.5139		0.3834		0.2368		0.4375
LB		0.5076		0.3349		0.1703		0.0784		0.2286

*p≤0.10 **p≤0.05 ***p≤0.001

7.4 Multiple negative binomial regression model for time spent on different care tasks

The following sections present the multiple negative binomial models that were built to explore factors influencing the time that unpaid carers spent on ADL, IADL and supervision, and to investigate whether there were differences between carer age and gender with respect to the time committed to caring. In a first step, I explored characteristics of the carer and the care-recipient by introducing the variables carer gender and age, co-residence, the relationship between carer and care-recipient, care-recipient gender and age and dementia severity to each model (see Chapter 3.6.3).

Two of the models, the model investigating time spent on ADLs and time spent on supervision by the interviewed unpaid carers, were no longer significant when all seven variables were introduced. Stepwise investigation of the models showed that the model focusing on ADL tasks achieved overall significance when the variables gender of the care-recipient and severity were removed. Similarly, the model on time spent on supervision by the interviewed unpaid carer achieved significance when removing dementia severity (see Table 7.3).

In these models a significant difference in the time spent caring between men and women could only be found in the model investigating time spent on IADL tasks, showing that women were likely to spend significantly more time on tasks such as preparing food, doing housework, shopping or assisting with transportation. This observation is consistent with the descriptive analysis presented in Section 7.2. Even though a slightly greater proportion of husbands than wives supported their care-recipients with IADL tasks, wives spent more time on average on each of the care tasks included in this category. Similarly, daughters consistently spent more time than sons on all of the tasks. The multiple regression models found no effect for carer age in any of the models. In addition, the variable ‘relationship’ only showed a statistically significant difference between the time spent caring by spouses and ‘other carers’ in the model investigating total time spent caring. The result suggests that ‘other carers’ spent less time on overall care than spouses. No statistically significant difference could be observed between the time spouses and filial carers spent on any of the care tasks explored.

A significant association found in all models investigated was co-residence with the care-recipient. Unpaid carers living with the care-recipient were found to spend significantly more time caring on all tasks than those living away from the person with dementia. Furthermore, in the three models, where it was possible to introduce the variable

dementia severity without the overall models becoming non-significant, statistically significant associations with the outcome variables were found. The model looking at time spent on IADL tasks showed that carers of both people with moderate and severe dementia spent significantly more time than carers supporting people with mild dementia. The same pattern was found in the model investigating total time spent caring. In the model focusing on supervision provided by all unpaid carers, carers looking after relatives with severe dementia were found to spend significantly more time on supervision than those caring for someone with mild dementia.

Overall, the pseudo r^2 of these models showed that the models explained relatively little variability, ranging from $r^2=0.01$ for the model on ADL tasks to $r^2=0.05$ for the model on time spent on IADL tasks.

Next, as outlined in Chapter 3.6.3, the variables that have shown a significant association in the univariate analyses were explored together with the key carer and care-recipient variables. Each of these models was developed using a systematic approach. First, the variables carer age and gender were introduced. Then in a stepwise fashion the variables relationship to the care-recipient, carer education, age and gender of the care-recipient and dementia severity were introduced to the models. In addition, variables that showed a significant association in the univariate analysis were explored. A variable estimating carer health was explored in each of the models, as ailing health was understood to be one of the factors limiting relatives' ability to provide care (Joling et al., 2015, p.1199; Oliver, Foot & Humphries, 2014, p.11). Findings from Chapter 4 support this hypothesis. There, a larger proportion of carers in the older age band than in the younger age band declared to be 'not in good health'. Where no significant association for one of the variables investigating aspects of carer health was found in the univariate analysis, the ordinal variable carer health was introduced to explore whether this improved the model.

After the introduction of each of the variables the Akaike information criterion was used to investigate whether the introduction of an additional variable improved the overall model (Akaike, 1974). In addition, a link test was performed to check the overall significance of the model (STATA, 2014). Additional variables were accepted to the model if they improved the model fit and the model remained statistically significant.

Table 7.4 Multiple negative binomial regression models for time spent on different aspects of unpaid care

Variables	**Time spent on ADL by all unpaid carers**		**Time spent on IADL by all unpaid carers**		**Time spent on supervision by all unpaid carers**		**Time spent on Supervision by interviewed carer**		**Total time spent on all care activities by all unpaid carers**	
	N= 242		N=242		N=242		N=222		N=242	
	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%
Carer gender										
Female	0.1716	-0.2587; 0.6018	0.5798***	0.2247; 0.9348	0.1826	-0.3521; 0.7173	0.1629	-0.3052; 0.6311	0.3871*	-0.0391; 0.8133
Carer age	-0.0092	-0.0424; 0.0239	0.0029	-0.0149; 0.0208	-0.0082	-0.036; 0.0198	-0.0069	-0.0315; 0.0176	-0.0051	-0.0272; 0.0169
Relationship										
Filial carer	0.2216	-0.7878; 1.2309	0.0062	-0.5739; 0.5863	-0.2873	-1.1885; 0.6139	-0.4819	-1.2661; 0.3023	-0.2063	-0.9243; 0.5117
Other unpaid	-0.7615	-2.0381; 0.5151	-0.5162	-1.2177; 0.1853	-0.8761*	-1.8372; 0.0849	-0.7928*	-1.6513; 0.0656	-0.9101**	-1.6792; -0.1409
Co-residence										
Yes	0.7927**	0.0622; 1.5232	0.8099***	0.4046; 1.2154	0.9661***	0.3659; 1.5663	1.2695***	0.7486; 1.7904	0.9354***	0.4555; 1.4153
Age care-recipient	-0.0126	-0.0498; 0.0244	-0.0021	-0.0219; 0.0178	0.0047	-0.0279; 0.0373	0.0089	-0.0195; 0.0373	0.0018	-0.0239; 0.0274
Gender care-recipient										
Female			0.2802	-0.0645; 0.6249	0.1259	-0.4167; 0.6686	0.2114	-0.2788; 0.7016	0.2537	-0.1699; 0.6772
Dementia severity										
Moderate			0.2642**	0.0373; 0.4912	0.3014*	-0.0274; 0.6302			0.3390**	0.0729; 0.6052
Severe			0.6448***	0.3959; 0.8936	0.5529***	0.1653; 0.9405			0.6362***	0.3243; 0.9481
Constant	1.0765	-0.8891; 3.0421	-0.4915	-1.6472; 0.6641	1.3547	-0.3692; 3.0786	0.9063	-0.5801; 2.3928	1.4774**	0.0939; 2.8608

*p≤0.10 **p≤0.05 ***p≤0.001

7.4.1 Multiple negative binomial regression model for time spent on Activities of Daily Living

The second model investigating time unpaid carers spent on ADLs included 221 observations. A statistically significant association was found for the variables carer gender, relationship to the care-recipient, co-residence, carer sleep-disruption, gender of the care-recipient and support from other carers (see Table 7.3.1). No statistically significant relationship was found between carer age and the time spent on ADL tasks.

In contrast to the first model, the second model showed a significant association between time spent on ADLs and carer gender, indicating that women were likely to spend more time on care tasks including personal care, dressing, eating and supporting the care-recipient in getting around indoors and outside the house. Furthermore, it was found that carers related to the care-recipient other than being their spouse or child spent significantly less time on ADL tasks than spouse carers. Consistent with findings from the first model, this model showed that carers living with the person with dementia spent significantly more time caring than those living independently of the care-recipient. While the introduction of the variable gender of the care-recipient violated the overall model fit in the first model, it became possible to explore the variable in the extended model. It was found that unpaid carers supporting women with dementia spent significantly more time on ADL tasks than carers supporting men.

Out of the variables that showed a statistically significant association in the univariate analysis, the variables carer sleep-disruption, carer health, support from other carers and care-recipient challenging behaviour were included in the final model. The variables measuring whether carers experienced sleep-disruption due to care-recipient's care needs showed the largest significant coefficient. This result indicated that carers who experienced sleep-disruption due to care needs were more likely to spend more time on ADL tasks. In addition, significant associations were found for the variable estimating support from other carers. It was found that carers receiving support from paid carers and those receiving support from both paid and unpaid carers spent significantly more time on ADL tasks than those receiving no additional support. No significant association could be found for carers receiving only unpaid care support. The significant associations with carer sleep-disruption due to care need and with receipt of paid and both paid and unpaid support might be indicators of carer needs. In the qualitative study presented in Chapter 5, spouses emphasised the wish to care for their relatives independently. Filial carers were more

willing to take up support from paid providers to fill care gaps. This might mean that carers in receipt of paid support and those that have to get up at night due to care demands provide care to a person with dementia with substantial care needs. Care need measured through the BADLs, as described in Chapter 3.6.3, could not be explored in this model as its introduction caused the overall model to be no longer significant. It was therefore not considered in the final model presented here. Finally, carers supporting a woman with dementia were found to be more likely to be spending more time on ADL tasks than carers looking after a man with dementia.

In comparison with the first model, this model was found to have an improved model fit. In addition, while the variability the model explained remained small (r^2=0.08) it was greater than the first model (r^2=0.01). Furthermore, post-estimation analysis exploring residuals indicated a good fit.

Table 7.4.1 Multiple negative binomial regression model for time unpaid carers spent on ADLs (n=221)

Variables	**Estimated coefficient**	**Confidence Intervals**
Carer gender		
Female	0.9232**	0.2111; 1.6354
Carer age	-0.0076	-0.0280; 0.0129
Relationship		
Filial carer	-0.6979*	-1.4355; 0.0396
Other unpaid	-2.8925***	-4.8635; -0.9215
Co-residence		
Yes	0.8941**	0.1502; 1.6379
Carer sleep-disruption		
Yes	0.7273***	0.3874; 1.0673
Carer health affected		
Yes	0.0915	-0.3038; 0.4868
Gender care-recipient		
Female	0.0928**	0.2192; 1.6367
Challenging behaviour (NPI)	0.1000*	-0.0005; 0.0205
Support from other carers		
Formal	0.5434**	0.0471; 1.0397
Unpaid	0.2149	-0.2026; 0.6324
Both	0.6604***	0.1685; 1.1523
Constant	-1.7479*	-3.7130; 0.2173

*p≤0.10 **p≤0.05 ***p≤0.001

7.4.2 Multiple negative binomial regression models for time spent on Instrumental Activities of Daily Living

The second model exploring IADLs included 222 observations and overall showed consistency with the first model. In both models, female carers were found to be

significantly more likely to spend more time on IADL tasks than male carers, and co-resident carers spent significantly more time caring than those not living with the person with dementia. No statistically significant difference was found for the variable carer age. In the first model, dementia severity was found to have a statistically significant association with carer time spent on IADL tasks. In the analysis of this model, there was an improvement when dementia severity was not included in the model. On the other hand, in this second model a significant association was found for carers related to the care-recipient other than being their spouse or adult child, while no such association could be detected in the first model. As in the second ADL model, other carers were found to provide significantly less time on IADL tasks than spouse carers. In contrast with results of the second ADL model, no difference could be found in the time carers spent supporting men or women living with dementia.

Among the variables identified from the univariate analysis and explored in this model, four statistically significant associations were found. Carers who experienced sleep-disruption due to care needs, carers who stated their health to be affected due to their care responsibility, carers who were not in employment and those experiencing challenging behaviour by the care-recipient were found to spend significantly more time on IADL tasks. As for time spent on ADL tasks, the BADLs score was also found to be significantly associated with time spent on IADLs. Introducing the variable to the model revealed multicollinearity. Exploring the model without the highly correlated variable NPI showed that the model had a higher AIC than the model including NPI but not the BADLs measure. In addition, after removing the variable NPI the overall model including BADLs was no longer statistically significant. For this reasons, the BADLs variable was not considered in the final model. In comparison to the first model this model improved in terms of overall model fit and variability explained (r^2=0.08). Post-estimation tests exploring residuals were consistent.

Table 7.4.2 Multiple negative binomial regression model for time unpaid carers spent on IADLs (n=222)

Variables	Estimated coefficient	Confidence Intervals
Carer gender		
Female	0.4101**	0.0668; 0.7533
Carer age	0.0005	-0.0117; 0.0127
Relationship		
Filial carer	-0.0108	-0.4296; 0.4079
Other unpaid	-0.9045**	-1.6799; -0.1292
Co-residence		
Yes	0.7154***	0.2965; 1.1343
Carer sleep-disruption		
Yes	0.3041**	0.1075; 0.5007
Carer health affected		
Yes	0.3153**	0.0802; 0.5504
Carer employment		
Not formally working	0.3015**	0.0247; 0.5783
OARS rating		
Mildly to moderately impaired	0.1672	-0.0951; 0.4295
Severely to totally impaired	0.0649	-0.2161; 0.3459
Gender care-recipient		
Female	0.3339*	-0.0098; 0.6778
Challenging behaviour (NPI)	0.0078**	0.0018; 0.0139
Constant	-0.9151*	-1.9599; 0.1297

*p≤0.10 **p≤0.05 ***p≤0.001

7.4.3 Multiple negative binomial regression models for time spent on supervision by all unpaid carers

The effect on gender found in the models for ADLs and IADLs was not observed in the model investigating the time all unpaid carers spent on supervision. As in previous models, no statistically significant relationship could be established between carer age and supervision by all unpaid carers. However, as in both ADL and IADL models, in this model I found that carers other than spouse and filial carers spent significantly less time on supervision. This association was not found in the first model investigating supervision by all unpaid carers.

Consistent with the first model, on the other hand, were the associations found for dementia severity and co-residence. Carers of people living with severe dementia spent more time on supervision than those supporting people with mild dementia. Furthermore, as in all other models, unpaid carers living with the person with dementia spent significantly more time supervising.

Among the other variables explored in this model, only the variable receipt of community care for the person with dementia showed a significant relationship. This result suggested that carers of people with dementia receiving community based services (paramedic, psychiatrist, GP, dentist, community psychiatric nurse, district nurse and/or practice nurse) spent more time on supervision than those who did not.

Implicit in this variable might be indicating greater overall care needs due to multimorbidity of the care-recipient. The introduction of the BADLs variable measuring care-recipients' needs caused the overall model to be no longer significant. This meant that the variable was not included in the final model.

In comparison to the first model, this model only marginally improved the variability explained (r_2^2 =0.02 versus r_1^2 =0.01) as well as the overall model fit (AIC_2=1620.5 versus AIC_1=1629.8). Post-estimation investigating residuals did not indicate any problems.

Table 7.4.3 Multiple negative binomial regression model for time all unpaid carers spent on supervision (n=240)

Variables	Estimated coefficient	Confidence Intervals
Carer gender		
Female	0.1431	-0.3692; 0.6555
Carer age	-0.0081	-0.0269; 0.0108
Relationship		
Filial carer	-0.1984	-0.8715; 0.4747
Other unpaid	-0.9082**	-1.8037; -0.0127
Co-residence		
Yes	0.8605***	0.2627; 1.4584
Carer employment		
Not formally working	0.2796	-0.1756; 0.7349
Carer health		
Good	-0.0881	-0.4321; 0.2558
Poor and very poor	0.1467	-0.3052; 0.5986
Gender care-recipient		
Female	0.1017	-0.4247; 0.6281
Dementia severity		
Moderate	0.2795*	-0.0441; 0.6032
Severe	0.5544***	0.1727; 0.9362
Care-recipient receipt community care		
Yes	0.7067**	0.0929; 1.3204
Constant	0.9670	-0.5538; 2.4878

*p≤0.10 **p≤0.05 ***p≤0.001

7.4.4 Multiple negative binomial regression models for time spent on supervision by the interviewed unpaid carer

As with the previous model, this next analysis focused on supervision, but only included the time the interviewed unpaid carer declared to spend. No statistically significant difference was found for the variables carer age or gender. Consistent with the first model exploring associations between time spent on supervision and carer and care-recipient characteristics (see Chapter 7.2), carers living with the care-recipient spent more time on supervision. In addition, significant associations were found for carers experiencing sleep-disruption and carers whose care-recipients received community-based services. The finding that people with dementia in need of

community medical care received more hours of supervision is consistent with results from the model investigating time spent on supervision by all unpaid carers (Table 7.3.3). In addition, it was found that carers experiencing sleep-disruption due to their care-recipient's care needs also spent more time on supervision. The introduction of the BADLs caused the overall model to be no longer significant. Therefore, the variable was omitted from the final analysis.

In comparison to the first model explored, this model showed very small improvements when investigating variability explained (r_2^2= 0.04 versus r_1^2=0.03) and the overall model fit (AIC_2= 1472.1 versus AIC_1=1492.6).

Table 7.4.4 Multiple negative binomial regression model for time the interviewed unpaid carer spent on supervision (n=221)

Variables	Estimated coefficient	Confidence Intervals
Carer gender		
Female	0.0208	-0.2408; 0.2823
Carer age	-0.0027	-0.0187; 0.0133
Relationship		
Filial carer	-0.1784	-0.6691; 0.3122
Other unpaid	-0.6499*	-1.3901; 0.0902
Co-residence		
Yes	1.1053***	0.5932; 1.6173
Carer sleep-disruption		
Yes	0.2692**	0.0187; 0.5197
Carer employment		
Not formally working	0.3694*	-0.0083; 0.7470
Carer health		
Good	-0.0854	-0.3835; 0.2127
Poor and very poor	0.0444	-0.3517; 0.4405
Care-recipient receipt community care		
Yes	0.6701**	0.1169; 1.2234
Constant	0.5524	-0.7632; 1.8679

*p≤0.10 **p≤0.05 ***p≤0.001

7.4.5 Multiple negative binomial regression models for total time spent caring by all unpaid carer

This final model focused on the aggregate time unpaid carers spent on ADL and IADL tasks as well as supervision. Carer gender and age were not found to be statistically significantly related to total time spent caring by all unpaid carers. In the first model the relationship to unpaid carers other than spouses or filial carers, co-residence and the provision of care for people with moderate and severe dementia were found to be significantly associated with more time spent on overall care. This second model was consistent with these findings. The only difference was that unpaid carers looking after people with moderate dementia were no longer found to be providing significantly more hours than carers supporting a person with mild dementia. The association for those caring for a person with severe dementia remained. In addition, the experience of sleep-

disruption due to care needs and the receipt of medical care and support for the person with dementia in the community were found to be significantly associated with greater numbers of hours of care provided by all unpaid carers. The introduction of the BADLs measure also caused this model to be no longer significant. This meant the variable could not be explored in the final model.

Table 7.4.5 Multiple negative binomial regression model for time all unpaid carers spent on total care (n=240)

Variables	Estimated coefficient	Confidence Intervals
Carer gender		
Female	0.1779	-0.0805; 0.4362
Carer age	0.0009	-0.0131; 0.0149
Relationship		
Filial carer	-0.0370	-0.5049; 0.4309
Other unpaid	-0.7239**	-1.3937; -0.0539
Co-residence		
Yes	0.8379***	03667; 1.3091.
Carer sleep-disruption		
Yes	0.3171***	0.0794; 0.5549
Carer health		
Good	-0.0229	-0.2992; 0.2533
Poor and very poor	0.1239	-0.2423; 0.4902
Dementia severity		
Moderate	0.2423*	-0.0275; 0.5119
Severe	0.5937***	0.2869; 0.9004
Care-recipient receipt community care		
Yes	0.5595**	0.0664; 1.0526
Constant	0.8381	-0.3925; 2.0687

*p≤0.10 **p≤0.05 ***p≤0.001

7.5 Discussion

In this chapter I investigated factors that influenced carer time spent on ADLs, IADLs, supervision and total time spent caring using cross-sectional data from the MODEM cohort study. The primary focus of this research, as in the other parts of the thesis, was on carer age and gender. My results suggest that women supporting people with dementia spent more time than did men on personal care tasks (ADLs) and on household tasks, shopping, laundry and transportation (IADLs), while no gender differences could be observed for supervision or total time spent caring. Furthermore, no statistically significant relationship between the variable carer age and any of the five outcome variables explored could be established. In addition, the variable reflecting the relationship between carer and care-recipient showed no significant difference in time spent caring between spouse and filial carers in any of the models. However, carers related to the person with dementia other than being their partner or filial carer were found to provide significantly less time compared to spouse carers on ADL and IADL

tasks, total time spent caring and the model including time spent on supervision by all unpaid carers. This difference disappeared when only considering the interviewed unpaid carer for the provision of supervision. A number of other variables explored in this analysis were also found to influence time spent caring. These variables include co-residence with the care-recipient, carer sleep-disruption, carer health, carer employment, dementia severity, challenging behaviour by the care-recipient, supporting a female care-recipient and care-recipient receipt of community care. A number of these different aspects will be discussed in the following.

Carer gender

The results of this study found that women spent more time on ADL and IADL tasks than men. Only one other study was identified that also reported statistically significant differences in time men and women spent on specific care tasks. This study, however, only investigated time spent on supervision as a proxy for carer burden. In contrast to the results of my study, where no statistically significant difference could be found between the time male and female carers spent on supervision, Haro and colleagues (2014, p.681) showed that female carers were more likely to spend less time on supervision. These latter findings were based on cross-sectional data from Germany, France and the UK. Wimo and colleagues (2002, p.261) investigating a cross-sectional Swedish sample, on the other hand, did not find a significant association between total time spent caring and gender (Wimo et al., 2002, p.261). Friedemann and Buckwalter (2014:322), exploring a predominantly Latino cross-sectional sample from the US, reported than men provided fewer care tasks than women, with the least amount being provided by sons. When considering gender patterns on unpaid care not limited to dementia care or specific care tasks, the evidence clearly shows that women in England and across the world provide longer hours of care than men (ONS, 2013a; Ferrant, Pesando & Nowacka, 2014).

The provision of personal care has been associated with increased burden among carers of people with dementia and poorer mental health (Holst & Edberg, 2011; Hiel et al., 2015). The literature further shows that with increasing hours of care, quality of life and well-being can be negatively affected (Bremer et al., 2015; Lethin et al., 2017; Covinsky et al., 2003). Across the literature, women have been found to experience greater burden and more symptoms of depression and anxiety than men when caring for a person with dementia (Campbell et al., 2008; Friedemann & Buckwalter, 2014; McDonnel & Ryan, 2011; Sutcliffe et al., 2017; Chappell, Dujela & Smith, 2015; Andreakou et al., 2016; Borsje et al., 2016; Fauth, Femia & Zarit, 2016; Gibbons et al.,

2014; Lethin et al., 2017; Orgeta & Lo Sterzo, 2013; Bookwala & Schulz, 2000; Borden & Berlin, 1990; Meshefedjian et al., 1998; Pinquart & Sörensen, 2006). Yet, little attention has been paid to exploring gender differences on time spent on different care tasks. The debate surrounding gender differences and the experience of burden among family carers suggests explanations such as gender differences in the use of coping mechanisms, differences in reporting, but also differences in social and cultural priming (Sharma, Chakrabati & Grover, 2016). The time men and women spend on specific care tasks, and the type of care provided might help to better understand why women tend to experience more negative outcomes from caring than men.

The results of the qualitative study reported in Chapter 5 picked up on a potential gender difference in expectations to take on care responsibilities. Daughters reported almost *'feeling groomed to be a carer'* and expressed recognition of gender and generational elements. As daughters, they were brought up with the expectation to raise children and to look after the extended family. Even though all daughters in the qualitative study had pursued a career while having their own family, several explained that they had voluntarily given up work in order to support their parents. A generational aspect might influence this observation. The Office for National Statistics reports that in 1984, approximately 49% of the population agreed with the statement 'a man's job is to earn money; a woman's job is to look after the home and family' (Scott & Clery, 2013). While the proportion of the public agreeing with this statement declined noticeably to 13% by 2012, many of the women currently in the position of looking after their parents with dementia are likely to have been influenced by views expressed in their formative years.

Wives did not speak directly about their decision to care, but instead some wives compared supporting their husbands with earlier experiences of childcare. As described in Chapter 5, one wife compared the relationship with her husband to '*mummy and her little boy'.* Toepfer, Foster and Wilz (2014) found similar comparisons: by associating dementia care with childcare it becomes more difficult for women to step away from care tasks or to accept help when the care-recipient is perceived to be fixated on the carer as little children can be on their mothers. Furthermore, some carers were described as seeking to fulfil the role of 'the ever-present mother' (Toepfer, Foster & Wilz, 2014, pp.241-242).

Men, on the other hand, as described in great detail in Chapter 5 and matched by the descriptive analysis in the presented chapter, showed somewhat different patterns. While most husband carers provided similar time on care tasks as did wife carers in the

sample, the few sons who participated in the study declared spending much less time on the provision of personal care tasks than any of the other carer groups. Sons in the qualitative study were found to largely avoid the provision of personal care to a parent with dementia. Instead, the men reported receiving support from paid carers, their sisters and wives on these tasks. This is consistent with findings from other studies (Campbell, 2010; Friedemann & Buckwalter, 2014). Campbell (2010), however, reported that sons' marital status influenced the intensity of care provided. Sons who described themselves as single and co-residing with their parents were more likely than married sons living with their own family to be involved in the provision of personal care.

Husbands, on the other hand, seemed to have taken pride in looking after their wives and some described the provision of care as learning new skills (Ribeiro & Paul, 2008, p.172; Calasanti & King, 2007, p.520). Consistent with the literature, several men reported adhering to a strict routine and using a somewhat detached, managerial approach in organising the different tasks required (Russell, 2007; Calasanti & Bowen, 2006, p.520; Sampson & Clark, 2015, p.6). With respect to IADL tasks, some husbands, such as one husband in the qualitative sample, described taking the liberty of avoiding activities they did not like very much and that were not deemed as vital: '*The ironing board: I lost that yonks ago'*. This might in part explain why husbands were found to spend less time on most IADL activities than wives (see Table 7.2.2).

As social and cultural shifts that relieve women from the expectation of having to give themselves up for others might be slow to come about, women could benefit from a greater availability of support with personal care tasks and opportunities of respite to reduce the level of burden experienced. Findings from this study and evidence from the literature suggest that not all care tasks are equally demanding. More work needs to be done to disentangle the effect of specific care tasks on carer well-being and quality of life in order to gain a better understanding of how best to support men and women of different ages supporting their relatives with dementia.

Carer age

As reported above, none of the models explored in this research showed a significant association between carer age and time spent caring. This is consistent with a number of studies investigating the association between total time spent caring and carer age (Jakobsen et al., 2011, p.424; Gervès, Chauvin & Bellanger, 2014, p.5; Neubauer et al., 2008, p.1169; Gustavsson et al., 2011). Only Wimo and colleagues (2002) reported a statistically significant relationship between carer age and the

provision of ADL tasks: they found that younger carers were more likely to spend more time on ADL activities.

The absence of a relationship between carer age and the time that carers spent on the different care tasks explored here could be due to the limited age range observed in the MODEM cohort (see Chapter 4). However, the provision of dementia care in large parts is driven by care needs (see Chapter 3.6.3) and, as discussed in Chapter 5, many elderly husbands and wives explained that their own health issues did not limit the amount of care they provided to their spouses. This is consistent with findings from analysis of carers using ELSA data: Vlachantoni (2010) found that the number of hours of care provided was positively associated with old age. The study further showed that over 50% of 'round-the-clock carers' were aged 65 and older (Vlachantoni, 2010, p.12). Similar results were found by Carmichael and Ercolani (2014, p.408) investigating data on unpaid carers from England. In addition, most spouses in my qualitative study reported supporting their partner with dementia without support from paid carers. One husband explained the inappropriateness of the service provided as a reason not to receive help. *'She said well they wouldn't get here till half seven, eight o'clock. I said 'well, that's no good'. Not being horrible, I know they wouldn't be there then, because [wife] is out of bed then'*. Another husband explained that his wife made clear that she does not *'want a teenager, […] [she does not] want a stranger in […] [her] house'.* The absence of differences in care provision by carer age, may therefore indicate that carers, irrespective of age, provide the amount of care their relatives with dementia need for as long as their own health issues do not prevent them from doing so. Providing intensive levels of care at older age, however, could have negative implications for people. As discussed in Chapter 6, older carers might be at greater risk of experiencing lower health-related quality of life and more symptoms of depression. More research investigating the impact of providing dementia care at different ages is required to better understand how carers can best be supported at different stages of their lives.

Relationship with the care-recipient

Related to the concept of carer age and gender is the relationship to the care-recipient. Analysis of the MODEM data showed that carers related to the person with dementia other than being their spouse or adult child were likely to spend less time than spouse carers spent on ADL and IADL tasks, supervision and total time. No statistically significant difference was found between spouse and filial carers in any of the models explored in this research. Other studies, in slight contrast, emphasise the time provided by spouse carers. A Danish study, for instance, showed that co-resident married care-

dyads spent more time caring than carers in other relationships to the person with dementia (Jakobsen et al., 2011, pp.423-424). Similarly, studies focusing on care receipt by the person with dementia showed that married people with dementia received more hours of care (Hajek et al., 2016; Neubauer et al., 2008, pp.1170-1171). Consistently, Neubauer and colleagues (2008) pointed out that co-resident spouses spent the longest hours caring, even in comparison to other carer groups who also lived with the person with dementia (Neubauer et al., 2008, p.1160). These results encourage the continuation of a policy focus on direct family members (spouses and filial carers) of people with dementia as they provide the largest bulk of care (ONS, 2013a).

Co-residence with the care-recipient

As pointed out towards discussing carer relationships, co-residence with the care-recipient was also found to be an important factor influencing all components of care investigated in this analysis. Living together with the person with dementia in all models explored was strongly associated with longer hours spent caring. The importance of co-residence as a determinant of availability was also found across the literature (Darbà, Kaskens & Lacey, 2015, p.901; Nordberg et al., 2005, p.867; Haro et al., 2014, p.681; Jakobsen et al., 2011, pp.423-424; Gervès, Chauvin & Bellanger, 2014, p.5). While these results perhaps were not surprising, they emphasise the importance of support for co-resident carers (see also Chapter 6).

Dementia severity, NPI and other forms of carer need

Other results from this study suggest that both dementia severity and challenging behaviour exhibited by the care-recipient influenced time carers spent on different care tasks. Dementia severity was found to be associated with time spent by all unpaid carers in the models investigating IADLs, supervision and total time spent caring. In the first model investigating time spent on IADLs and total time spent caring, carers of people with both moderate and severe dementia were found to spend more time than carers of people with mild dementia. This was different in the second models exploring supervision and total time spent caring, where a significant difference was only found between carers of people with severe dementia and those with mild.

A number of studies from a variety of countries - including Sweden, France, the Netherlands, Germany and Spain - have also found positive associations between unpaid care time and dementia severity, suggesting that with increasing severity carers provide longer hours of care (Gervès, Chauvin & Bellanger, 2014; Darbà, Kaskens & Lacey, 2015; Bakker et al., 2013; Hajek et al., 2016; Haro et al., 2014; Wimo et al.,

2002; Bell, Araki & Neumann, 2001). An increase in time spent caring by severity was also found in the cross-sectional analysis of a British sample. This effect, however, was lost over time (Lenox-Smith et al., 2016). Two studies that undertook similar analysis to the work presented in this study also found associations between dementia severity and time spent caring. Wimo and colleagues (2002) found that time spent on ADLs was influenced by severity and challenging behaviour, while a Czech study found that cognition of the person with dementia influenced both ADL and IADL but not supervision (Holmerova et al., 2017).

Care-recipient challenging behaviour, commonly measured in UK and other European studies with the NPI, in this study was associated with increased time spent on IADLs. The study by Wimo and colleagues (2002), on the other hand, reported an association between challenging behaviour and time spent on ADLs. The relationship between challenging behaviour and greater care commitment was also echoed in other research. Haro and colleagues (2014), for instance, found associations between different NPI sub-scores and carer supervision time. Similarly, a study investigating samples from Spain, Sweden, and the UK as well as a German study found challenging behaviour to be influencing the overall amount of time spent caring (Gustavsson et al., 2011; Michalowsky et al., 2016). This evidence suggests that care need, driven by severity and challenging behaviour, contributed to care time.

As described in Chapter 3.3.1, the data we collected as part of the MODEM cohort study allowed me to explore variables in relation to care time that have not previously been explored. In the literature estimating cost of unpaid care based on the RUD measure, some attention was paid to the concept of carer sleep with respect to capping the hours carers declare on supervision in order not to overestimate costs (Neubauer et al., 2008). Studies reported estimating that carers could get eight hours sleep per night, while evidence from the literature suggests that significant proportions of carers experience sleep-disruption due to care needs of the person with dementia (Simpson & Carter, 2013a; Creese et al., 2008; Arber & Venn, 2011). So far only one study has asked carers about the number of hours of sleep they get per night to make meaningful adjustment (Gustavsson et al., 2011). In this study I could not adjust the number of hours carers declared to be spending in a meaningful way (see Chapter 3.6.2). However, it was possible to explore the introduction of a dichotomous variable exploring the association of sleep-disruption with time spent caring. The results showed that the experience of sleep-disruption due to care needs had a significant association with time carers spent on ADL and IADL tasks, time spent on supervision by the

interviewed carer and total time spent caring. Arber and Venn (2011, p.158) who qualitatively investigated the provision among older carers at night found that sleep was disrupted due to care-recipients' physical needs, disruptive night-time behaviour, monitoring and surveillance of the care-recipient, anticipation of needs and worries and anxieties that kept the carer awake. Carers were also found to experience disrupted sleep patterns after their care responsibility had ceased. The night time care needs of people with dementia need to be considered when designing interventions and policies to support carers providing care in the community settings in order to reduce carer burden as well as negative implications for carer physical and mental health (Creese et al., 2008).

Carer health

Another set of variables explored in this analysis was the association between time spent caring and carer health. In this study, three variables estimating carer health were introduced into the models. No association was found between either a categorical or continuous measure of carer health and any of the five outcome measures in the univariate analysis. However, a binary variable measuring whether or not carer health had been affected by caring showed a significant positive association with the time spent on IADL tasks, suggesting that people whose health had been affected provided more hours than those whose health had not been affected. Few previous studies have investigated the relationship between health and time spent caring. A Dutch study focusing on societal cost of unpaid care found that higher caregiver cost, which was comprised of time spent caring as well as other incurred costs, was associated with chronic illness (Joling et al., 2015). Similarly, a study investigating eight European countries including the UK found a negative relationship between time spent caring and psychological well-being. Among carers in the UK and in France, being a carer was associated with greater use of health care resources (Bremer et al., 2015). In addition, an American study found that carers of people with dementia were more likely to 'experience increased frailty over time' than carers supporting people without dementia (Dassel & Carr, 2016, p.451).

It is well known that increasing numbers of older people, often living with multimorbidities themselves, support their spouses with care needs (Audit Commission, 2004, in Oliver, Foot & Humphries, 2014, p.11). As shown in Chapter 5 and discussed in this chapter with respect to carer age, many spouse carers of people with dementia living in ill-health put the health and well-being of their partner ahead of their own. GPs and specialists supporting people with chronic and long-term illnesses as well as social

care providers undertaking needs assessments need to be aware of people's care responsibilities and support should be made available to enable carers to look after themselves.

Employment

The variable employment in this study was dichotomised into people volunteering and working in paid jobs and carers staying at home, being retired, unemployed or declared to be full-time carer for their relative with dementia. In both models on ADLs and IADLs, carers who were not formally working provided significantly more hours of care than those in employment or volunteering. This is consistent with findings in the literature indicating that carers in employment tend to provide less hours of care (Wimo et al., 2002; Gustavsson et al., 2011; Bakker et al., 2013; Michaloswky et al., 2016).

Receipt of support

Another set of variables that was possible to explore was related to the influence of support on time spent caring. Receipt of medical services in the community for the person with dementia and support received from paid and/or unpaid carers was associated with more time spent caring in several models. The receipt of community medical care by the person with dementia was significantly associated with supervision by all carers as well as by the unpaid carer interviewed for this study and with total time spent caring. Support from other carers (formal, unpaid and both) was also positively associated with time spent on ADL tasks. This might suggest that care-recipients received medical care in the community and the people with dementia whose carers received formal or unpaid and formal support may have greater care needs. The findings of a study by Gervès, Chauvin and Bellanger (2014) support this complementary hypothesis, which suggests that unpaid and paid care increase simultaneously with increasing needs rather than paid services substituting for family support.

Limitations

The detailed collection of time that carers spent on specific care tasks is frequently used to estimate the costs of unpaid care. Only a limited amount of evidence can be found in previous studies on the factors influencing time that carers spend supporting their relatives with dementia. The results presented in Chapter 5 show that time is inherently linked to carer well-being, as one important coping mechanism identified was finding time for oneself. It has been established that carers of people with dementia tend to provide longer hours of care than carers of people with other illnesses (Oliva-Moreno et al., 2017). Investigating factors influencing the time that carers spent

is therefore important to get a better understanding of how carers could be supported in their role to reduce the negative implications on their physical and mental health. Further research should explore aspects influencing time spent caring over longer time horizons than was possible here, because the effects, as discussed in Chapter 6, are likely to accumulate over time and cross-sectional analysis can only provide a situational snapshot.

In this analysis, as previously noted in Chapter 3.6.3, it was impossible to explore the influence of ADL and IADL abilities of the care-recipient and their influence on time spent caring, because introducing the BADLs variable caused the regression models no longer to be significant. Gustavsson and colleagues (2011) found that the care-recipients' ADL and IADL abilities were even stronger predictors of care need than severity or NPI.

Furthermore, it is important to use time measures estimating relevant care time appropriately. The RUD builds an important foundation for this. Amendments to the RUD, as described by Neubauer and colleagues (2008) and in this study, show that it is important to collect information not just on the primary carer, but also on other unpaid and paid care to get a fuller picture of the overall care situation. Furthermore, information on hours of sleep, such as collected by Gustavsson and colleagues (2011) can help to provide a more informed understanding of the care responsibility. Both of these points have been recognised as relevant by the authors of the RUD measure (Wimo et al., 2013a, p.432).

Cès and colleagues (2017) in a systematic review on time measures, suggested further relevant components, such as time spent on 'finding the person if they get lost' and 'finding things that are lost' as well as eliciting information on time that a carer spends on care management ('making appointments and arrangements for the provision of care') or on home adaptations. This information could again improve our understanding of the tasks that make up the provision of unpaid care for people with dementia (Cès et al., 2017, pp.234-235). On the other hand, information on how much time carers can use for themselves (as in the questionnaire used in the present study), could help to reduce the risk of overestimating time. Further thought also needs to be given to overlap in time across care activities (Cès et al., 2017, pp.234-237).

Chapter 8

Discussion and Conclusion

My thesis, focusing on the well-being and quality of life of men and women of different ages providing unpaid care to a relative with dementia in the community, highlights the importance of mental health to people's ability to live well. Larkin, Henwood & Milne (2018) pointed out that in much research focusing on carer well-being, quantitative assessment tools are used to assess the impact of interventions, without taking into account the complex, subjective experience of the carers concerned. In this research I investigated the well-being and health-related quality of life of unpaid carers of people with dementia using a mixed methods approach, bringing together qualitative data based on people's accounts and experiences and quantitative evidence allowing for the observation of and examination of patterns of effects among larger groups.

8.1 Key findings from the thesis

I began with a review of the literature using a systematic approach to respond to the research question 'How is carer well-being and quality of life conceptualised and measured in the literature?' It became evident that while there was not one consistent scale used to measure well-being, the majority of studies investigates carer mental health, focusing particularly on depression and anxiety or the absence thereof. This is consistent with findings by Richard Layard, who investigates well-being over the life-course among the general population by focusing on life satisfaction. Flèche and Layard (2017, p.28) argued that mental illness 'explains more of the variance of misery than is explained by […] physical illness'.

Quality of life, on the other hand, has been measured principally using four different scales. All scales covered the components mental health, physical health and ability to engage in an active life and therefore fit with the NICE definition, which outlined health-related quality of life as: 'a combination of a person's physical, mental and social well-being; not merely the absence of disease' (NICE, 2017a). Two of the quality of life measures additionally covered aspects of relationship, environment, finances and other components and so provided a more complex picture of quality of life. Comparison of well-being and quality of life measures showed considerable overlap in the two concepts and emphasised the importance of mental health. All well-being and quality of life measures identified in the review, no matter how different their definitions, captured symptoms of depression and anxiety.

Next, in Chapter 4 I responded to the research question 'Are the characteristics of unpaid carers in England comparable to unpaid carers of people with dementia in the datasets START, SHIELD-CSP-RYCT and MODEM'? I explored carer characteristics in the dementia-specific MODEM cohort study and the two dementia-specific randomised controlled trials START and SHIELD-CSP-RYCT. Then I compared those with carer characteristics in ELSA (Wave VI) and the Population Census 2011, two population datasets capturing population-representative information on carers in England. I found that overall carer characteristics in MODEM, START and SHIELD-CSP-RYCT were similar to a subgroup of carers in ELSA, who provided support to people aged 65 and older. This suggests that even though none of the datasets are population representative by design, their samples appear to reflect well characteristics of carers for older people in England. Comparison with Census (2011), where data could not be limited to care provision for elderly people, showed slightly greater differences. This tentatively suggests that carers of older people in the community, including people with dementia, might be somewhat different in their characteristics than carers of children and adults of all age groups with care needs.

Consistent with the literature, all datasets showed that proportionately more women than men provided unpaid care. This substantial difference between gender, consistent with national statistics, disappeared in the older age band capturing carers aged 75 and over in all of the datasets (ONS, 2013a; ONS, 2016a). This was driven by the proportional increase of male carers in the older age band. A slightly larger proportion of men and women in ELSA than in Census identified as carers in this age band. In comparison to both these datasets, the proportion of both men and women in the older age group in the three datasets START, SHIELD-CSP-RYCT and MODEM were even larger. However, among two of the dementia-specific datasets, the gender difference was still marked. Even in the older age group, approximately six percentage points more women were found to provide care in MODEM and SHIELD-CSP-RYCT.

The observation that proportionately more older people were involved in the provision of dementia care, and that in two of the datasets the gender difference remained among the older age band could be related to sampling. However, it could also indicate that carers of people with dementia in comparison are older and, while the proportion of elderly men supporting their spouses increases with age, women continue to carry the bulk of the care responsibility (Dury, 2014). In order to test this hypothesis, it would be necessary for larger samples of dementia carers to be collected than were available to me in this study.

In Chapter 5 I presented the results of the qualitative study with 25 participants who were also part of the MODEM cohort. In this study I responded to the research question 'Are there differences in how husbands, wives, daughters and sons of people with dementia experience the provision of care and how they construct well-being?' My research identified six components that influenced carer well-being. First, carers used a range of coping mechanisms to deal with the everyday challenges of their responsibilities. As their responsibilities increased, all carers emphasised the importance of finding time for themselves as a key coping mechanism. Women expressed greater difficulty in leaving their care-recipient with someone else and finding appropriate replacement care. The difficulty that women often have in stepping back from the high expectations they have of themselves may be an underlying factor, which makes taking breaks more difficult for women. Sons, on the other hand, were found to be more protective of their own life and able to create clearer boundaries with respect to their involvement in the provision of personal care, while daughters showed patterns of care similar to those of spouses (Campbell, 2010; Grigorovich et al., 2016; Ferrant, Pesando & Nowacka, 2014). This pattern was consistent with the meantime that the four groups spent caring, as explored in Chapter 7.

Second, the quality of the relationship with the care-recipient framed carers' experiences and influenced their well-being. Where carer and care-recipient had a good relationship before care needs emerged, carers were motivated to reciprocate the many years of support the care-recipient had given to them before their illness. I found this motive to be particularly strong among husbands and daughters. Other carers, in line with Nancy Folbre (2001), may have altruistic motives or feelings of responsibility. The notion of reciprocity in dementia care is often criticised due to the degenerative nature of the illness. However, husbands who reported their wives' expressions of appreciation for their care and/or the appreciation of their family and friends for the support the men provide to their wives, found these experiences of appreciation and recognition to be great drivers of motivation. It is perhaps telling that none of the women interviewed in this study expressed recognition of their support by their husbands as equally rewarding. Wives, on the other hand, did not explore their specific motivation: caregiving, for them, as found by Simpson and Carter (2013b, p.118) appeared to be mostly part of their marital obligations.

Constructive support from family and friends was identified as a third component influencing carer well-being. In my study, husbands were found to have more active support networks that allowed husbands to take breaks, while women were more likely

to talk about family and friends that would provide emotional support. Similar patterns were identified by Sharma, Chakrabati and Grover (2016), who investigated carers supporting people with mental illnesses. Husbands and wives differed somewhat in their expectations from their support networks. Wives seemed to have lower expectations regarding the support their own children could or should provide, emphasising the importance of their independent lives and responsibilities, while a some husbands expressed disappointment about the limited availability of their children. The sons interviewed for this study all received support from either a sister or their wives. Some daughters with brothers, on the other hand, expressed frustration about the absence of practical support provided by their brothers, and reported unsolicited advice on how parental care should be handled as unhelpful.

The fourth component I found to be facilitating carer well-being was the concept of safety and security of the care-recipient. Here, spouses, who in most cases lived with health problems themselves, emphasised the importance of a procedure that would ensure their partner with dementia would be looked after in a way that would meet their needs and preferences should something happen to the carer. Filial carers were more concerned with their parents' physical safety when they were left on their own as well as the risk of accidents among people with dementia who exhibited wandering behaviour.

Fifth, my qualitative study further identified several external facilitators to well-being, including members of the medical profession, home care and institutional care providers as well as the voluntary sector. Participants in the qualitative study made clear that GPs played a crucial role not just in aiding a diagnosis, but also in unlocking access to social services, creating links to services provided by the voluntary sector and by recognising that besides being a husband, wife, daughter or son, relatives needed to be recognised in their carer role. Several husbands reported supportive GPs who also recognised the carers' needs. Women, on the other hand, found it more difficult to be recognised in their carer role and to make their needs heard by the medical profession or by social care services.

Nearly all filial carers eventually purchased additional support through paid care services. Among the filial carers who used home support, sons expressed frustration when their mother did not receive the quality of care and emotional support they expected. Daughters appeared to use paid home care support only where they could not provide the services themselves and therefore had limited expectations of the specific tasks that were provided. At the time of the interviews all but one of the filial carers had

moved their parents into institutional care. In comparison with daughters, sons moved their mothers into care earlier (López et al., 2012). However, they maintained their carer role by regularly visiting and monitoring the quality of care provided. Filial carers uniformly expressed the view that their well-being improved after the move into institutional care, even though the decision around institutionalisation and the practicalities involved were experienced as complex and draining.

None of the spouses with dementia lived in institutional care. Spouses particularly engaged with services provided by the voluntary sector. These included joint activity clubs and carer groups. Couples participating in joint activities enjoyed the possibility of maintaining an active lifestyle in a protected environment and also were able to grow a new social network of people in similar situations. While this and the exchange with other carers in carer groups were helpful for some, other spouses declared that they did not want to get too immersed in these groups, as they preferred not to think too much about what the future would hold for the couple. They felt that being in this environment would regularly expose them to their underlying concerns. I could not detect gender patterns with respect to this behaviour.

The final component facilitating carer well-being from the qualitative study I identified was carer health. Most carers experienced health issues of their own. Husbands in particular emphasised that their physical health issues were under control and not affecting their well-being. However, most carers also spoke about experiencing symptoms of depression and anxiety. Some carers had previously experienced mental health issues, but several men and women reported having become more anxious since providing care for their relative with dementia and expressed this experience, consistent with Richard Layard's findings, as most debilitating (Clark et al., 2017, p.126).

In Chapter 6 I responded to the research question 'How do well-being and quality of life of male and female carers for people with dementia of different ages change over time?' The time period under investigation was 12 months. For this purpose I built multiple regression models using the three dementia-specific datasets MODEM, SHIELD-CSP-RYCT and START. Health-related quality of life in all three datasets was measured using the EQ-5D. Analysis of the START dataset (after imputation for missing values) found that older carers were more likely to experience lower health-related quality of life over time. My results from the analysis of SHIELD-CSP-RYCT showed that women experienced lower health-related quality over time. This finding is consistent with results from a cross-sectional Canadian study (Gibbons et al., 2014), but other research has suggested no gender or age difference (Argimon et al., 2004;

Aravena, Albala & Gitlin, 2018; Arango Lasprilla et al., 2009; Bell, Araki & Neumann, 2001). However, these results were observed in cross-sectional studies, as no longitudinal studies focusing on carer gender and age could be identified. In addition, in my research, statistically significant associations with the variable relationship were found. In the START complete case analysis, other carers were found to experience better health-related quality of life than spouses and in SHIELD-CSP-RYCT filial carers were found to have better health-related quality of life than spouses. This suggests that spouses' health-related quality of life might be more affected over time than that of filial carers and other family and friends providing dementia care.

Carer well-being, in line with findings from the literature review I presented in Chapter 2, was investigated using the HADS depression scale and the General Health Questionnaire. Analysis of SHIELD-CSP-RYCT showed that older carers were more likely to experience fewer symptoms of depression at follow-up. MODEM complete case analysis, on the other hand, found that older carers had worse psychological health. However, the statistical significance of the relationship was lost following imputation.

Contrary to previous literature, which consistently reports women to experience worse mental health, gender did not show a statistically significant difference in any of the models I investigated (Andreakou et al., 2016; Borsje et al., 2016; Fauth, Femia & Zarit, 2016; Gibbons et al., 2014; Lethin et al., 2017; Orgeta & Lo Sterzo, 2013; Bookwala & Schulz, 2000; Borden & Berlin, 1990; Meshefedjian et al., 1998; Pinquart & Sörensen, 2006). This suggests that in the datasets I explored the well-being of men and women was similar. Yet, as with the results for health-related quality of life, spouses were also found to be more likely to experience depressive symptoms using SHIELD-CSP-RYCT. On the other hand, complete case analysis of START showed that carers related to the care-recipient – other than being their spouse or adult child – were more likely to experience depressive symptoms than spouses.

The final set of questions explored the concepts happiness, personal growth and life satisfaction. I explored these questions using Personal Well-being questions included in the MODEM cohort study and a component of the HSQ questionnaire collected in START, which focused on happiness. Complete case analysis of MODEM data showed that female carers were less likely to rate highly on the happiness scale or on life satisfaction. However, in both cases this effect was lost following imputation. No associations for carer age and relationship were found. Similarly, no statistically significant differences were observed for any of the independent variables of interest when investigating personal growth.

In the final empirical chapter, I investigated factors influencing the time carers spent on IADL and ADL tasks, supervision and the total time spent caring. The research question examined was: 'What factors influence the time commitment of different tasks by men and women of different age groups caring for a relative with dementia?' For this analysis I used cross-sectional data. The analysis showed that women spent significantly more time on ADL and IADL tasks. No age difference could be observed regarding the time spent caring for any of the groups. With respect to the variable measuring relationship, the group 'other carers' were found to spend significantly less time on ADL, IADL, supervision by all unpaid carers and total time spent caring. Several other variables in this exploratory analysis also showed significant associations. In all models, I found that co-resident carers spent significantly more time on the different care tasks investigated than carers who lived away from the person with dementia. Carers who stated that their health was affected by caring and those who were unemployed spent more time on IADL tasks. In addition to carer characteristics, some other variables related to the care-recipient were found to influence time spent caring. Furthermore, carers who experienced sleep-disruption spent significantly more time on ADL and IADL tasks, supervision provided by the interviewed carer and total time spent caring.

The experience of sleep-disruption due to care needs could be considered as an indicator of care need (Simpson & Carter, 2013a; Creese et al., 2008; Arber & Venn, 2011). Furthermore, sleep-disruption is associated with health implications (Creese et al., 2008). Carers who received formal and both formal and unpaid support were found to spend more time on ADLs, while carers whose care-recipient received community care spent more time on supervision and total time spent caring. This might also be associated with greater care need. In addition, carers of people with moderate and severe dementia spent significantly more time on supervision and total care, while carers of people with dementia displaying challenging behaviour spent more time on IADL tasks.

8.2 Why gender, age and relationship matter when discussing carer well-being and quality of life

I found the data sources MODEM, SHIELD-CSP-RYCT and START to be consistent with population-representative datasets in England and indeed the wider literature by containing a greater proportion of women supporting a relative with dementia in the community (ONS, 2013a; ONS, 2016a; Carmichael, 2011; Ferrant, Pesando & Nowacka, 2014). The gender discrepancy, as presented in Chapter 4, was particularly wide among the younger age group, where the majority of carers were women. In the

older age band this difference narrowed, showing that a larger proportion of men beyond retirement age provided care for their spouses with dementia. These findings confirmed that the traditional gender divide in unpaid care as of yet has not been closed and that women continue to provide the largest share of unpaid care, and also spend significantly more time than men on personal care tasks and in support with instrumental activities (Chapter 7) (Carmichael, 2011; ONS 2013a; ONS, 2016a).

8.2.1 Women disproportionately worse off

These results in isolation do not sound problematic. However, spending substantial numbers of hours caring, and particularly the provision of personal care tasks (ADL), have been associated with greater burden, lower psychological well-being and greater healthcare utilisation by the carer (Covinsky et al., 2003; Holst & Edberg, 2011; Hiel et al., 2015; Costa et al., 2012; Bremer et al., 2015; Lethin et al., 2017). Across the literature, women experience greater burden and more symptoms of depression (Campbell et al., 2008; Friedemann & Buckwalter, 2014; McDonnel & Ryan, 2011; Sutcliffe et al., 2017; Chappell, Dujela & Smith, 2015; Andreakou et al., 2016; Borsje et al., 2016; Fauth, Femia & Zarit, 2016; Gibbons et al., 2014; Lethin et al., 2017; Orgeta & Lo Sterzo, 2013; Bookwala & Schulz, 2000; Borden & Berlin, 1990; Meshefedjian et al., 1998; Pinquart & Sörensen, 2006). In part, this is consistent with results from my research, where, as presented in Chapter 6, women were found to be more likely to rate their health-related quality of life lower than men after one-year follow-up in the model using data from SHIELD-CSP-RYCT. However, no significant difference between carer gender was found in the other two models or for the models investigating depressive symptoms and psychological health. Nevertheless, complete case analysis of the MODEM dataset showed that women rated happiness and life satisfaction lower than men. These results indicate that women may be at greater risk of experiencing lower well-being and quality of life when they engage in the provision of dementia care.

As I pointed out above, the largest discrepancy in care provision with regards to carer gender can be found among carers aged 50 to 75 (Chapter 4), with considerably more women than men providing care. In this group, a substantial proportion of people support a parent with dementia, but also a not inconsiderable share of people care for a spouse with dementia.

In my analyses, consistent with the wider literature, it became clear that patterns of care among male and female filial carers are different (ONS, 2013a; ONS, 2016a; Carmichael, 2011; Ferrant, Pesando & Nowacka, 2014). Descriptive analysis in Chapter 7 showed that daughters exhibit care patterns in intensity comparable with spouse

carers, while the few sons providing care were found to spend the least amount of time on any of the care tasks investigated. Evidence from my qualitative interviews with a sub-sample of carers in MODEM provided insights into these care patterns. While daughters reported close relationships and the desire to reciprocate parental support, as well as the need to satisfy family and societal expectations as motivations to care, sons described situations where no other family member was able or willing to take responsibility for their parent with dementia. Daughters, often faced with dual responsibility towards their own family and their parent with dementia, found it difficult to limit their involvement and reported feelings of guilt when having to consider respite care options so that the family could take a break. Sons, as also reported previously in the literature, took more managerial approaches (Campbell, 2010; Grigorovich et al., 2016).

This meant that sons primarily took responsibility for the organisation of care, rather than providing it themselves. While parental well-being was important, sons – when compared with daughters – were able to draw much clearer boundaries between their own needs and those of the parent (Grigorovich et al., 2016). As part of the managerial approach, adult sons in this study all received practical and emotional support from their wives or sisters, while a couple of daughters expressed frustration about the lack of involvement of their brothers. Similarly, sons made greater use of paid services, but voiced frustration when quality of care purchased did not match their expectations (Grigorovich et al., 2016). Daughters, by contrast, primarily purchased care to fill gaps. In the literature, the relationship status of sons was identified as a 'decisive factor' in whether men engaged in hands-on care, with single men being more likely to be actively involved in the care provision (Friedemann & Buckwalter, 2014, p.327; Campbell, 2010). None of the men in this thesis were in this situation.

8.2.2 The association with age is not straightforward

The differences in care patterns observed between sons and daughters disappeared when comparing the support that husbands and wives provided to their spouses with dementia. Comparison of time spent on different care patterns (Chapter 7.2) showed much smaller differences. As most of the spouses were elderly themselves, this carer group should not be discussed without paying attention to carer age. The findings in Chapter 7 showed that carer age did not significantly affect the time spent on care tasks, but spouses were found to spend more time on personal care tasks (ADLs) than filial carers or carers related differently to the person with dementia. This is an important result, as it means that older carers were likely to spend equal amounts of time on the

different care tasks, despite their age putting them at greater risk of frailty (Gale, Cooper & Sayer, 2015). These older, predominantly spousal carers have previously been identified as a vulnerable carer group (Vlachantoni, 2010).

Analysis in Chapter 6 showed that older carers and spouse carers were more likely to experience worse health-related quality of life over time than younger carers and carers supporting parents and other relatives or friends with dementia. These findings were consistent with results suggesting that older carers of people with dementia experience greater frailty and incur higher health care costs than their peers who did not provide dementia care (Dassel & Carr, 2016; Gilden et al., 2014). However, as stated above, these findings could not be established consistently across the datasets examined in this thesis. A report on inequalities in later life stated that both physical and mental health in later life were strongly associated with socioeconomic factors (Scharf et al., 2017, p.3). The reliance on trial and cohort data for this thesis, and particularly their geographical locations and recruitment strategies may have meant that participants were socio-economically more homogenous, which could explain the absence of differences found.

Furthermore, the absence of differences in time spent caring suggests that older carers provide equally intensive support as younger carers. In addition, spouse carers were found to spend significantly more time on personal care tasks than filial carers and carers related to the care-recipient in other ways. This is consistent with Carmichael and Ercolani's study (2014, p.414), which suggested that older carers who live with their care-recipient 'are among the most intensive carers who care for the longest hours', and who were frequently involved in the provision of personal care. The association between time spent caring and co-residence was also shown in Chapter 7.

Yet, evidence of the well-being and quality of life of carers in this group is mixed (Greenwood & Smith, 2016; Ask et al., 2014; De Oliveira, Vass & Aubeeluck, 2015). Analysis of SHIELD-CSP-RYCT data in Chapter 6 showed that, while carers of older age were less likely to experience depressive symptoms, spouses were at greater risk. In the MODEM complete case analysis, on the other hand, older carers were found to be more likely to have lower psychological health, and in the START complete case analysis carers related to the care-recipient other than being their spouse or filial carer were found to be at greater risk of depressive symptoms than spouse or filial carers.

Similar discrepancies were found in the literature. A cross-sectional Norwegian study found that caring for a spouse with dementia was associated with lower life satisfaction and a greater risk of experiencing symptoms of anxiety and depression (Ask

et al., 2014, p.413). Similarly, a literature review found that advanced carer age was associated with lower quality of life (De Oliveira, Vass and Aubeeluck, 2015, p.18). Greenwood and Smith's review (2016, p.165), on the other hand, suggested that while older carers are at greater risk of experiencing health problems, they reported more positively on their care experience and were more likely to identify rewards from their role compared to younger carers (Greenwood & Smith, 2016, p.165). The only study identified that followed spouse carers longitudinally found that, while the provision of care increased the risk of experiencing depressive symptoms, it was not possible to establish an elevated risk over time (Capistrant, Berkman & Glymour, 2014, p.4).

These varying results, in the absence of a substantial body of literature focusing on carer age, suggests that older carers, and particularly spouses, may not have had much choice in whether or not to engage in the care of their partners, but could also point towards underlying effects of socioeconomic factors accumulated over life (Greenwood & Smith, 2016; De Oliveira, Vass & Aubeeluck, 2015; Scharf et al., 2017). Most spouses live together, and many couples look back to decades of shared lives. In order to maintain this unit, spouses were likely to engage in considerable and demanding care tasks.

Depending on their own health status, the provision of care might be more or less difficult to pursue. In the qualitative study (Chapter 5) all spouse carers reported the experience of physical health problems, but at the same time emphasised that these conditions did not limit their ability to support their spouses with dementia. In a study among elderly Latino carers, participants recognised that, with ailing health, the provision of care became more burdensome; nevertheless, spouses continued to be motivated to maintain their care responsibility and ultimately the spousal unit (Friedemann & Buckwalter, 2014, p.328). However, even though spouses in my qualitative study did not ponder over their own physical health, they were aware that their frailty could potentially limit their ability to support their partner with dementia. Two spouses expressed concerns about what would happen to their care-recipient if something happened to them and expressed frustration that they could not prepare an emergency route similar to advanced directives, which would enable them to formally communicate the preferences of the couple to family, health and social services in the case of an emergency.

Spousal relationship quality prior to the onset of dementia might act as a moderating effect to spouses' desire to care (Quinn, Clare & Woods, 2009). Some studies suggest that greater marital closeness creates a protective effect around a

spouse's quality of life, whereas others found that spouses who expressed greater marital closeness experienced worse quality of life and more symptoms of depression and anxiety over time (Stensletten et al., 2014; Fauth et al., 2012). In the empirical work reported in this thesis, the motivation to care due to many years of close relationship was overwhelmingly expressed by husbands. Wives, on the other hand, experienced the onset of dementia in their husbands as a narrowing of opportunities that they had been looking forward to in their retirement. One woman described as feeling sent back to being housebound similar to what she experienced when her children were small, only with the loss of a partner and the awareness that his cognitive abilities would not improve. Simpson and Carter (2013b, p.118) described the female experience as marital obligation.

Other potential moderators are coping strategies, which have been hypothesised to explain gender differences in quality of life and well-being. It is frequently emphasised that women are more likely to employ emotion-based coping strategies, such as denial or self-blame, which – as shown in Chapter 6 – are associated with greater symptoms of depression but also with a greater experience of care burden (Geiger et al., 2015). Men, instead, are associated with strategies such as problem-solving or detachment (Sharma, Chakrabati & Grover, 2016, p.12; Hong & Coogle, 2016; Calasanti & King, 2007). However, neither the concept of relationship closeness nor that of coping mechanisms appears to sufficiently explain differences in carer well-being and quality of life.

In the following I will build on the results of Chapter 5 and then present my argument. I will firstly argue that gender, age and relationship differences in well-being and quality of life observed are based on the experience of lifetime inequalities due to socially accepted and socially encouraged gender roles. Secondly, I will focus on the importance of mental health to carer well-being and argue that in order to address well-being and quality of life in dementia care, underlying gender concepts in mental health need to be addressed.

8.2.3 Why men might do better

As described above, daughters reported family and societal expectations to care; similarly, wives experienced the provision of care for their husbands as a continuation of lifelong responsibilities focused around the family. Husbands, on the other hand, while also experiencing the loss of a partner, described learning to recognise the needs of their wives and the acquisition of new skills to satisfy these as well as the skills necessary to maintain the couple's everyday life (Atta-Kondadu, Keller & Daly, 2011; Calasanti & Bowen, 2006). Men expressed pride in a number of abilities, such as

cooking, maintaining the house, thinking of approaches to best support their spouse's needs or learning to put on their wife's make-up. Despite the mutual experience of loss, men were able to affirm 'their identity as male protector and provider' and experienced forms of personal growth, while women maintained a role that had been socially ascribed most of their life (Hayes, Zimmerman & Boulstein, 2010, p.1112). The female experience as an 'extension of their usual role' and the adherence with family and societal expectations was also reported by Calasanti & King (2007).

Furthermore, several husbands reported how the appreciation and affection their wives showed towards the support they provided boosted the men's morale. In addition, husbands reported receiving recognition and appreciation for the care they provided by their families and other carers in their networks. This is consistent with findings by Ribeiro & Paul (2008, pp.175-176), who concluded that men who recognised the provision of care as a 'continuation and deepening of their affective involvement' were able to draw meaning and satisfaction from caregiving. Lloyd, Patterson & Muers (2014, pp.21-22) further described this recognition that husbands' experienced as a form of social honour. None of the wives reported such an experience explicitly. Calasanti and Bowen (2006, p.262) suggested that female awareness of care tasks led wives with dementia to appreciate the support they received, while husbands with dementia – besides a potential lack of awareness of their wives' care responsibility – also might have struggled with losing their role as 'household head'. This internal conflict might explain why some wives expressed such frustration and resentment towards their husbands' behaviour.

In the interviews conducted for this thesis, as in the literature, husbands report using skills acquired during their professional lives (Milligan & Morbey, 2016). Husbands described how their professional experiences helped with their approaches to their spouse's care needs and in navigating health and social services. A number of husbands further reported to have taken on ambassador roles with the aim to improve the situation of people with dementia and their carers in society. Men took these roles in formal capacities when participating as expert advisors to research projects, ambassadors for charities but also as individuals, such as the husband who sought out local banks to sensitise managers towards the needs of people with dementia. Therefore, men were able to develop almost a second career after retirement. Wives, on the other hand, felt relegated into patterns of early motherhood. Toepfer, Foster and Wilz (2014) found a similar discourse that associated dementia care to childcare and motherhood among a sample of women, but also in the media representation of a large national

newspaper in Germany. The authors identified the care-recipient's fixation on the carer, the carer's limited availability to pursue independent activities and the carer's understanding of the care-recipient's needs (even where verbal communication no longer is possible) as attributes of motherhood. My qualitative research allowed me to compare the experience of men and women, and while husbands experienced similar care patterns as described in Toepfer, Foster and Wilz' article, none of the men used the association with fatherhood. Perhaps women's traditionally greater involvement in childcare and their greater likelihood of identification with motherhood as a 'full-time job' could explain the use of this comparison among wives and daughters.

Further differences were found in the availability and utilisation of unpaid and paid support. In Chapter 5 I reported that husbands, in comparison to wives, had greater support networks that enabled the men to find moments for themselves. This support was mostly provided by their daughters, their wives' relatives and friends. Some wives reported receiving occasional support from their daughters, but mostly reported the emotional support provided by children and friends. Pinquart and Sörensen (2006, p.39), in their meta-analysis of gender differences among carers, suggested that 'lower levels of social resources' negatively affect women's psychological and physical health. Perhaps the greater willingness of friends and family to practically support husbands is linked to the recognition men receive for overstepping traditional barriers of masculinity and engaging in traditionally female tasks. Women, on the other hand, might experience greater expectations with respect to their marital and family duties. Eriksson, Sandberg and Hellström (2013, p.164), who observed similar a support pattern in their Swedish sample, proposed that these predominantly female networks – while supporting the women – might also act 'as a way to discipline' gendered patterns of care through 'constant introspection and self-examination' of their female role.

Consistent with the literature, both husbands and wives in the present study showed reluctance in seeking unpaid support, particularly where they felt that their children carried enough responsibilities for their own young families and did not want to put more pressure on them (Friedemann & Buckwalter, 2014; Sanders, 2007; Zodikoff, 2007). Nevertheless, husbands expressed greater frustration when their children did not provide the support they would have expected.

However, husbands participating in the qualitative study showed greater ability in taking up practical support that allowed them to create opportunities to pursue their interests. Women expressed this desire, but found its realisation difficult to achieve in practice. Ashida, Marcum and Koelhy (2018, p.446) found that, independent of gender

or relationship to the care-recipient, carers who felt supported by family members experienced significantly lower levels of distress than carers who did not feel adequately supported.

In line with the gender pattern among filial carers explored previously, spouse carers received unpaid, informal support overwhelmingly from their daughters. The exception was one son who lived with his parents and supported his mother jointly with his father. A limitation to the availability of unpaid care was the fact that many families were geographically dispersed, with children living too far away from their parents to provide regular support (Meulen & Wright, 2012). One husband pointed to the educational achievements of his daughter, which led her to have job responsibilities that did not allow her to actively support her parents. The husband compared her situation to women with lower educational achievements working locally, which would allow the latter to fulfill this role. While this carer expressed great pride in his daughter's achievements, this comparison for his daughter rather than the sons clearly shows underlying gendered expectations towards women.

Carers interviewed in the study reported in this thesis invariably emphasised that access to social services and therefore to paid and formal support was enabled through a diagnosis, with the GP's recognition of dementia playing a major role. Women reported greater difficulty in being recognised as carers and having their concerns heard not just in communication with GPs but also with social services. However, both men and women whose expectations of support were not matched with the support they or their care-recipient received from medical and social services and, indeed, support received from carers' social network, felt let down and that may have affected future attempts to obtain support (Neufeld & Kushner, 2009). Particularly daughters and some of the sons reported having to fight to get their needs heard.

Besides medical support and some help from social services, spouses did not purchase much paid support. One husband reported that available home care services did not match the couple's lifestyle patterns, while another husband explained that his wife would not accept a carer coming to the house. Low uptake of services among spouse carers has also been described in the literature. Studies focusing on this aspect reported barriers to be lack of information, feelings of responsibility and guilt towards the spouse, previous negative experiences and unavailability of services (Neufeld & Kushner, 2009; Zodikoff, 2007; Baker, Roberston & Connelly, 2010; Greenwood & Smith, 2015). Contrary to the common discourse that husbands' were less inclined to take up services than wives, several husbands reported their wives' use of day care

(Greenwood & Smith, 2015; Baker, Robertson & Connelly, 2010; Robinson et al., 2014). The discourse on gender difference in take-up of paid services could not be explored in great detail in the present study because men in the qualitative study cared for wives with more advanced forms of dementia than the partners of female carers. The literature suggests that men are less willing to take up such support. Husbands in this study explained that services available did not fit their needs or that that their wives did not want to have someone coming to the house.

This evidence suggests that men and women, sons and daughters, husbands and wives experience the provision of dementia care differently and therefore are likely to experience varying impact on their well-being and quality of life. Husbands, even though they are likely to fall into the elderly carer group and frequently experience their own health issues, rate their well-being and quality of life highest as they can learn new skills, maintain social status as well as a meaningful role post-retirement. They also receive more support, which enables the men to find little pockets of time to pursue their own interests. Wives, brought up in a generation where women were raised to primarily support the family, continue to provide care at a time in their lives when particularly the younger generation expected to have time to pursue their own interest. Daughters, despite carrying the responsibilities for their own families and work, feel socially pressured to conform to the gender norm and to become carers of their parents. Only sons appeared able to limit their hands-on involvement, but still experienced negative outcomes, such as depression and anxiety when carrying the responsibility for their parents with dementia.

8.3 Addressing differences in carer well-being and quality of life

8.3.1 Lifetime inequality

Based on the results of this thesis, and the discourse in the wider literature, I suggest that the difference in well-being and quality of life between men and women of different ages and in different relationships to the care-recipient with dementia are based on socially engrained understanding of male and female roles that lead to different experiences accumulated over the life-course. Elderly spouse carers seem to be able to overcome underlying assumptions of masculinity, which allows them to take on different carer roles than sons. This new role, coupled with the experience of personal growth and social status, might be an underlying factor in explaining why elderly men caring for their spouses were found to report better quality of life and well-being (Atta-

Konadu, Keller & Daly, 2011; Baker, Robertson & Connelly, 2010; Pretorius, Walker & Heyns, 2009).

Women provide care throughout life

The results of my research confirmed that women of all ages continue to provide the bulk of unpaid care. The comparison of datasets in Chapter 4 highlighted this by showing that there were not just larger proportions of women providing care in the age band 50 to 74, but that this trend continued in both the START and MODEM samples among the age group 75 years and older. Some might argue that the unequal distribution of care provision between men and women was linked to choices within families, where members with the lowest opportunity cost (linked to the lowest income) are most likely to take on care. However, it seems that the argument of choice is somewhat flawed.

Historically, care has been the realm of women, an observation Graham (1983, p.18) famously described with the words 'caring is 'given' to women, it becomes the defining characteristic of their self-identity and their lifework. At the same time, caring is taken away from men: not caring becomes a defining characteristic of manhood'. Even though this observation was made in the 1980s, it maintains a certain validity among men and women of working age providing care, when excluding the provision of childcare. Data on the provision of adult care provided by the Office for National Statistics, which includes care to people aged 18 years and older in the UK, does not just show that women of all ages provide the majority of care, but also that the time women of all ages spent caring increased between the year 2000 and the year 2015 by 67% for women under 30, by 27% for women aged 30 to 49 years and by 21% for women aged 50 and older. Over the same time period, there was a rather different picture for men. The time men aged 50 and older spent caring, who as observed in this thesis are the group of men most involved in unpaid care, increased by approximately 15%. This increase still falls short of the increase in time spent caring by women of the same age group. Furthermore, where women of all ages were found to spend more time on unpaid care between the years 2000 and 2015, the time men younger than 30 and the time males aged 30 to 40 years spent caring decreased by 49% and 67%, respectively (ONS, 2016a, pp.12-13). These data confirm that, consistent with the results of my research, the gender gap in care provision is not diminishing and that women are considerably more likely than men to provide substantial care for adults with care needs over the life-course. The recognition that care patterns are not changing is important when thinking about how to support men and women in these roles in future.

The recently celebrated century since Women's suffrage shone a light on the achievements gained in working towards a society in which men and women can live equally. Women are increasingly educated and free to choose their occupation (Roantree & Vira, 2018, p.5). However, McGuiness (2018, p.7), using data from the Office for National Statistics, showed that approximately half of women in 2017 worked as 'nurses, teachers or other educational professionals'. Only 8% of women reported to be working as managers, directors or senior officials, while this was the case for 13% of men. This supports the argument that women brought up in gendered environments, where care and altruism are still associated with female qualities (Folbre, 2001), are more likely to pick professions that allow for reduced and flexible working hours, perhaps with an underlying anticipation of potential care roles.

Furthermore, following decline of the breadwinner model and the increasingly prevalent dual-earner model, which has been observed in Britain over the past 50 years, the proportion of female employment increased from approximately 57% in 1975 to 78% in 2017 (Scott & Cleary, 2013; Roantree & Vira, 2018). While this development has given women independence to pursue careers and lifestyles of their choice, it also created a policy environment in which every individual is required to contribute to the labour market in order to protect themselves from old age poverty (Lewis, 2006). A report on poverty and gender identifies 'access to an adequate independent income over the life course for women and men, and fairer sharing of caring and the costs of caring both between women and men in household and more widely' as the main underlying issues of gendered poverty (Bennett & Daly, 2014, p.10). Yet, women disproportionately continue to step back from the employment market in order to support relatives with care needs. Data for the UK show that women continue to be more likely than men to be employed in part-time roles (McGuiness, 2018). This represents a historic pattern, which enabled women to adhere to work and family responsibilities (Lewis, 2006, p.105). A report by the Institute for Fiscal Studies further emphases the implications of child care on the gender wage gap, showing substantial differences in wage development between men and women emerging following the birth of children (Costa Dias, Elming & Joyce, 2016). Furthermore, an estimated 1.86 million women were economically inactive due to family commitments; this was the case for only 242,000 men during the same time period (McGuiness, 2018; ONS, 2018).

Gabriele Winker (2015, p.10) convincingly argued that in capitalist societies investments are placed where profits can be made. The labour- and time-intensive nature of care traditionally does not provide scope for large profit margins, but instead

creates substantial costs. Therefore care is pushed into the unpaid realm of the home, provided primarily by women. Daughters, in my study, expressed feelings of being expected, coerced or socially primed to take on responsibility for their parents. This means that women of working age frequently experience not just the dual responsibility of working and caring, but also are more likely to limit their employment opportunities to positions that enable the flexibility to manage this dual responsibility and to accept reduced social security contributions which can leave them in more vulnerable positions later in life.

Next, elderly women providing predominantly spousal care are likely to have experienced even stronger views on gender roles during their lives. Data from the British Social Attitudes survey shows that agreement with statements, such as 'a man's job is to earn money; a woman's job is to look after the home and family' has reduced from 49% in 1984 to 13% in 2012. These women are likely to have experienced more extended periods in their lives during which they provided care at home (Scott & Cleary, 2013).

Men in this study were found to benefit from learning new roles, drawing from skills developed during their professional careers and receiving recognition and social status in their carer role. Women did not report such experiences. Perhaps gender differences in carer well-being and quality of life in part can be explained by this lack of recognition, jointly with the almost lifelong experience of carrying family responsibility - from helping out their mothers with looking after sibling, raising a family while pursuing a career, to looking after ageing parents and parents-in-law and/or their own partners. The notion of 'mummy and her little boy' exemplified this situation of reoccurring responsibility. Perhaps societal expectations that women should do it all, without receiving recognition of the multiple responsibilities carried and holding back on pursuing careers, make women more prone to feeling depressed and anxious and low in self-esteem, which ultimately puts at risk their well-being and quality of life.

Elderly men report gains when overcoming static masculinity

Men, on the other hand, as expressed by Graham's (1983) quote above, historically were denied the opportunity to care. For a long time men were expected to be the strong, detached, sole breadwinners and heads of families (Hanlon, 2012). This, as shown in both dementia-specific data, but also by data on more general unpaid care provision, might still hold true to a degree for men of working age who continue to limit their active involvement in care provision and instead pursue full-time careers. The frequently deployed argument of opportunity costs between men and women,

suggesting that disproportionate female engagement in unpaid care was due purely to economic choice, might in part reflect the remaining labour market segregation, which means, as described above, that men are more likely to seek out careers in well-paid, private sector jobs (Lewis, 2006, p.109; Costa Dias, Elming, & Joyce, 2016; ONS, 2016a; McGuinness, 2018).

This picture shifts substantially among older, retired men. With increasing male longevity, more couples can expect to grow old together. As old age is also associated with more health issues, older men are likely to experience that their wives develop care needs. However, while the provision of care among older men appears to be directly driven by their partner's need, this might be accompanied by a relaxation of masculine expectations following retirement. One husband in the sample analysed in Chapter 5 described how admitting to his work colleagues that he provided personal care to his wife would have been difficult, but following retirement he does not have to share this information in the workplace. A similar argument was put forward by Calasanti and King (2007, p.526), who argued that younger men might be more prone to retaining 'ideals of younger, occupationally base masculinity', which involved limited expression of emotions, such as fear or shame, 'successful performance in the face of others' objections' and a focus on task-oriented solutions.

Relaxation of a relatively stringent understanding of masculinity and taking on a 'second career' in which husbands find purpose and gain new skills and social status, as well as receive appreciation and gratitude, might be a combination that helps to protect men's quality of life and well-being. This is consistent with a hypothesis developed by Baker, Robertson and Conelly (2010, p.325). They added that the understanding of masculinity might affect husbands' experiences. Men with traditional concepts of masculinity might describe experience gain from caring and learning new skills in the household, while men with less traditional concepts may not experience this gain as they were more involved in care and household tasks throughout their lives. Research on masculinity theory and age further confirms the observed shift. It is suggested that the retirement accompanying curtailment of the professional identity might emphasis 'sociability, business and networks' (Milligan & Morbey, 2016, p.113). In contrast, however, results from a study investigating associations between traditional masculinity and carer strain and gain among older husbands of women with dementia did not find significant associations, suggesting that 'gender identity does not predict how they adapt to becoming a caregiver' (Baker, Robertson & Connelly, 2010, p.324). As the number of men and women providing care for their relatives with dementia increases,

more attention should be paid to underlying factors, such as gender and age, which influence carer well-being and quality of life.

8.3.2 The importance of carers' mental health

The second aspect this thesis emphasised was the importance of mental health when aiming to support and improve the well-being of family carers of people with dementia. This result was supported by the recently published NICE guidelines, stating that carers of people with dementia 'are at an increased risk of depression' (NICE, 2018, p.32). The review presented in Chapter 2 showed the strong link between the concepts of well-being and quality of life with depression and anxiety. The relevance of mental health was further supported through findings reported in Chapter 5.They not just showed that independent of age and gender most carers in the qualitative study experienced mental health issues while caring for their spouse or parent with dementia, but also made clear that experience of anxiety and depression to people with a care responsibility is more debilitating and limiting than the experience of physical ailments. These findings are consistent with results from the World Happiness Report (Clark et al., 2017, p.126), which showed that in all Western countries analysed, including the UK, 'diagnosed mental illness emerges as more important than income, employment or physical illness'.

While results from my research cannot confirm gender differences in depression and psychological health, the dementia-specific literature overwhelmingly reported gender differences in depression, with women experiencing worse mental health (Andreakou et al., 2016; Borsje et al., 2016; Fauth, Femia & Zarit, 2016; Gibbons et al., 2014; Lethin et al., 2017; Orgeta & Lo Sterzo, 2013; Bookwala & Schulz, 2000; Borden & Berlin, 1990; Meshefedjian et al., 1998; Pinquart & Sörensen, 2006). This was also found across society in general (Baker, 2018; Karger, 2014). Indeed, the meta-analysis by Pinquart and Sörensen (2006a, p.39) showed that gender differences among carers were even more pronounced than differences in the general population. Recent mental health statistics for England suggest that common mental disorders (including depression, anxiety, panic disorders, phobias and obsessive compulsive disorder) were more common among females than males across age groups (Baker, 2018, p.4). Furthermore, out of the 893,000 people entering treatment through the IAPT programme for a common mental disorder in 2016/17, 62.5% were women. The gender difference in accessing treatment remained consistent among the population aged 65 and above. Over 5% of people who entered treatment in this age group were women, while among men it was only 2.5% (Baker, 2018, p.3). Yet, suicide rates for men are

higher than for women across all ages, with men being at greatest risk at age 45 to 59 (ONS, 2017a).

These results mandate the question do traditional scales investigating mental health or mental illness address appropriately what are described in the literature as predominantly male symptoms? Martin, Neighbors and Griffith (2013, p.1100) hypothesise that 'traditional' symptoms of depression may be 'at odds with societal ideals of masculinity'. In their study they explored whether the inclusion of symptoms such as anger attacks, aggression, substance use, risk-taking and hyperactivity affect the prevalence of depression in their sample, and in particular, whether this affected the prevalence of depression by gender. The study showed that men were significantly more likely to report these externalising symptoms than 'symptoms such as withdrawal from friends, sleep problems, and feelings of complaintiveness' (Martin, Neighbors & Griffith, 2013, p.1104). This hypothesis is supported by evidence from Magovcevic and Addis' (2008, p.118) study, which found that men who endorsed more externalising symptoms also showed greater 'adherence of hegemonic masculinity roles'. Calasanti and King (2007, p.526) hypothesised whether underlying concepts of masculinity might be a reason that expression of anger tends to be socially acceptable for men in most circumstance, while emotional responses might call into question their competence or ability to respond to problems.

Contrasting prevalence of depression by gender following the inclusion of 'alternative and traditional' symptoms of depression showed that equal proportions of men (30.6 %) and women (33.3%) live with symptoms of depression (Martin, Neighbors & Griffith, 2013, p.1100). These results are consistent with findings by Genuchi and Mistunaga (2015) who assessed depression using the Masculine Depression Scale (Magovcevic & Addis, 2008), which includes externalising symptoms of depression, among undergraduate students in the United States as well as by Azorin and colleagues (2014), who investigated gender differences among a cohort of major depressive patients in France. On the other hand, Möller-Leimkühler and colleagues (2004), who analysed a sample of psychiatric inpatients in Germany did not find a statistically significant difference between men and women in endorsing 'masculine' symptoms of depression. These findings call into question whether men are done justice by a discourse that suggests that men are less prone to experience depressive symptoms. Reconsideration of the scales used to assess depression may be appropriate, particularly as mental health has been identified to be a primary predictor of well-being (Clark et al., 2017).

A focus on male experience of depression and anxiety would also be supported by findings from this thesis. Even though quantitative findings from Chapter 6, using traditional measures for depression and psychological health, did not conform with the wider literature identifying gender difference in depression, results from my qualitative study (Chapter 5) support the notion that some men may experience more externalised symptoms of depression. In the qualitative interviews both men and women spoke about their experiences with depression and anxiety. While women reported more traditional symptoms, such as feeling sadness, some men described different routes to their diagnosis. One husband described how the family became alerted to his mental health issues when he became '*very snappy, very on edge […] [and] a bit uptight'* (Husband 5) and one son was diagnosed with anxiety after getting painful tensions in his leg.

The openness with which both men and women discussed their experiences of mental health issues could be an indicator that participants in the study did not experience substantial stigma attached to their diagnosis while caring for a relative with dementia. The gender difference in 'readiness to disclose negative feelings and health problems' as observed by Pinquart and Sörensen (2006, p.39) could not be confirmed in this study. However, the interview participants only made up a small proportion of the overall MODEM sample and people agreeing to participate in qualitative research on carer well-being may be more willing to reveal such information than carers who declined participation.

Besides, the absence of gender differences with respect to depression and psychological health in Chapter 6 could have a number of explanations. First, differences in outcome measures over the period of one year were only marginal, which may have affected potential differences. Second, carers enrolled in the three studies investigated volunteered their participation and particularly husbands, as identified in Chapter 5, described becoming advocates for their wives' and their own needs. Taking up the role of an advocate may have affected their responses. Third, the age range of carers in this thesis, particularly for men, was relatively small with men being on average around 70 years old in SHIELD-CSP-RYCT and MODEM and slightly younger in START. As discussed above, results in this thesis and the wider literature provided mixed messages with respect to age and mental health. However, the limited age range and the fact that the majority of male carers in this study were husbands, who as discussed above may experience more positive outcomes from their care commitment than wives, could also offer a potential explanation for the absence of statistically significant gender difference. Nevertheless, the findings of the present study, in contrast

to findings from other studies, together with the growing discourse on defining and measuring mental health in light of potential gender constraints warrant further study. The thesis emphasised the importance of mental health to carers' well-being and quality of life. More should be done to support men and women of different age groups and in different relationships to the people with dementia they support in order for them to be able to live well.

8.4 What are the policy implications of this study?

My study has shown that women of all ages provide the majority of care for people with dementia and that a substantial proportion of older men care for their spouses. While my research does not confirm the well-established gender differences with respect to mental health, the findings make clear that mental health aspects play an important role when considering well-being and quality of life. Furthermore, my qualitative research showed that men and women equally and irrespective of their relationship to the care-recipient experienced depressive symptoms and anxiety, and those who received support greatly benefited from it. It becomes clear that in an environment where policy-makers pass substantial responsibility for the provision of dementia care to the family, carers require support, which reflects their characteristics and needs to protect their quality of life and well-being.

In Section 8.3 of this chapter I discussed underlying social inequalities, for which, as Jane Lewis (2006, p.110) aptly phrased it, 'there is no magic bullet'. Persisting gender inequalities over the life-course cannot be solved with policy approaches focusing solely on care but must be addressed in all social realms and need to grow over time. This, however, does not mean that men and women of different ages and in different relationships to their care-recipients could not be supported better today through policies addressing their immediate needs.

The English Government enacted the Care Act in 2014, introducing a policy framework which requires local authorities – besides supporting the person with dementia – to 'support the well-being of carers', to 'contribute to […] the development by carers in its area of needs for support', and to 'improve the quality […] of support for carers' (Care Act, 2014, p.3). The Care Act further provided carers with the 'legal right to assessment and support' (NICE, 2018, p.8). A recent update to the NICE guidelines on dementia additionally recognised carers' needs for support and endorsed the provision of psychoeducation and skills training in order for carers to be informed about dementia and to gain an understanding on how to 'respond to changes in behaviour' and to adapt communication, to develop strategies and skills to deal with

challenges, to plan meaningful joint activities with the care-recipient, to learn how to look after 'their own physical and mental health, and their emotional and spiritual well-being' and to receive information about available services and how to access them (NICE, 2018, pp.43-44). The NICE guidelines further emphasised the importance of support being available following diagnosis and in line with carers' needs and preferences, as well as being available locally. Informing and involving carers in decision-making, where appropriate and in agreement with the person with dementia, was also recognised as important (NICE, 2018, pp.1-43). Finally, the greater likelihood of experiencing depression among carers of people with dementia and the need to support carers in this domain have been recognised.

Unfortunately, over recent years cuts in government funding of services available to people with moderate or 'low-level' care needs and their carers have meant that carers', rather than receiving the support recommended, find themselves in a position of carrying even greater responsibilities for the care-recipients' needs (Burchardt, Obolenskaya & Vizard, 2016, p.196). Burchardt, Obolenskaya and Vizard (2016, pp.195-197) reported that government spending began flattening in 2009/2010 and started falling in 2010/11. The reduction in spending was found to particularly have affected people aged 65 and older, a population group proportionally increasing in size due to population ageing and with increasing demands towards the health and social care system, as increasing age is associated with frailty and support needs (Burchardt, Obolenskaya & Vizard, 2016, p.195). While services for people with more intensive needs expanded, services for people with moderate needs decreased, leaving many people with care needs in fragile situations (Burchardt, Obolenskaya & Vizard, 2016, p.201). The reduction in services available to people aged 65 and older also affects people with dementia, who, as discussed above, in their majority fall into this age group, and leaves unpaid carers picking up the pieces. It is also important to emphasise that a substantial proportion of carers of people with dementia are elderly themselves and if left to manage the support of their partners with dementia without support, might become at risk of needing support themselves. This would likely increase the cost of care.

In the following I will outline six concrete suggestions to support carers based on the findings from my research. In addition, I will provide some suggestions regarding further research that could contribute to filling knowledge gaps identified in this thesis.

First, carers should have access to effective interventions that help to prevent and address depression and anxiety. Second, carers should be supported in finding time for

themselves to be able to pursue their personal interests and to maintain their social network. Third, carers benefit from a single point of contact to help them navigate the many different service providers available, and access to these services needs to be improved. Fourth, the Dementia Strategy 2012 identified a crucial role for GPs in facilitating diagnosis and therefore access to services. GPs need to receive training and resources to support carers of people with dementia in meaningful ways. Fifth, together with the person with dementia and with help from social services, care dyads across the country should have the possibility to develop personalised emergency routes in case something happens to the main carer. Finally, policies to support non-primary carers in their ability to support family members with dementia could enable a wider sharing of responsibilities between family members. In addition, they may encourage family cohesion and reduce carer burden.

8.4.1 Support to address mental health issues

Several evaluations of specific, short, group and individual counselling interventions have been found to effectively reduce depression among family carers of people with dementia (Gallagher-Thompson et al, 2012, p.323; Mittelman et al., 2008; Livingston et al., 2014b). One of those interventions was START, an 'eight-session manual-based coping intervention delivered by psychology graduates to individuals'. One of the datasets, which I was allowed to use for the research reported in this thesis, tested this intervention (Livingston et al, 2014a, p.7). Over time, the START intervention was found to be cost-effective and clinically effective in both reducing and preventing depression for several years after the intervention took place and interventions of its kind have been recommended in the updated NICE guidelines (Livingston et al, 2014b; Knapp et al, 2013; NICE, 2018).

Other types of interventions that were found to contribute to carer well-being by reducing stress and depressive symptoms included psychoeducational programmes, specialised skill training, multi-component interventions, psychotherapy and some technology-supported interventions (Gallagher-Thompson et al., 2012; Elvish et al., 2013). The example of a joint reminiscence intervention for both carer and care-recipients highlighted the importance of thorough evaluation of programmes before implementation. While some beneficial effects were found for the people with dementia participating in the intervention, carers showed significantly higher levels of anxiety after attending several sessions (Woods et al, 2012).

My research demonstrated the importance of recognising the diversity of carers providing dementia care. Carers may identify with several identities: they can be men

and women, spouses or filial carers, and people of different ages. Caution should be taken in recognising the potentially differing needs, but also perhaps the different approaches required to respond to these needs when designing and implementing interventions (Roberts & Struckmeyer, 2018). The START intervention, for instance, overcame barriers that may have prevented carers from participating by offering to meet people in their own homes and by seeing some of the participants in the evenings (Livingston et al, 2014b, p.547). Elvish, Cawley & Keady (2014, pp.59-60) described the importance of the therapeutic relationship, particularly where the relationship with the person with dementia has been affected. The availability of services that provide carers with a 'safe space' and constructive support is crucial to their ability to provide care for their relative with dementia but also to support their own well-being and quality of life.

8.4.2 Time for themselves – improved access to carer allowance & respite care

Unanimously, co-resident carers in the qualitative part of my thesis expressed the need for time for themselves, and those who managed to find a little time to pursue their own interests and to maintain their social networks emphasised the benefit of these opportunities. In the literature, traditional respite care options, ranging from day care and community-based respite care to institutional respite, have been discussed with respect to offering carers time for themselves. A number of sons, daughters, husbands and one wife reported that their care-recipient attended day care services, some filial carers reported the use of residential respite care and other filial carers had experience with live-in carers. Yet, uptake of respite care options among carers of people with dementia is reported to be low (Vandepitte et al, 2016). Underlying reasons suggested were a lack of information, inappropriate timing of information, carer feelings of guilt and failure when taking breaks from their care responsibility, resistance from family and/or the person with dementia as well inadequate services and concerns about quality of services (Roberts & Struckmeyer, 2018; Neville et al., 2015; Singh et al., 2014). Three steps towards acceptance were identified as crucial for carers to accept respite support: first, recognition of the need to get out; second, 'giving themselves permission to leave it temporarily' and third, the availability of resources which enable carers to take breaks (Neville et al., 2015, p.53; Strang & Haughey, 1998).

Evidence of the effectiveness and cost-effectiveness of different respite services in the literature was moderately positive. Day care was viewed as a largely positive intervention that allowed carers to respond to other demands in their lives and to 'recharge' from their everyday care responsibility (Roberts & Struckmeyer, 2018, p.9).

Qualitative evidence of community-based respite care, in line with the experience of the daughters in this thesis, was found to be supportive for carers (Lethin et al., 2017, p.530). However, other evidence suggested that carers were concerned about the quality of care provided and felt their continuous presence was important to reassure the care-recipient (Singh et al., 2014, p.6). Reliability and trust in the replacement carer was identified as crucial to the success of community-based respite (Singh et al., 2014, p.6). A systematic review investigating effectiveness of respite interventions could only identify one methodologically weak study. Nevertheless, the results pointed towards 'reduced caregiver morbidity' (Vandepitte et al, 2016, p.1287).

The third respite opportunity discussed in the literature was institutional respite. Only some filial carers in the samples described in Chapter 6 reported the use of institutional respite care when they had to go away. Similarly to day care, results from the systematic review suggest that institutional respite was associated with reduced carer burden and stress, and fewer behavioural problems of the person with dementia (Vandepitte et al, 2016, p.1284). However, a study investigating the effect of burden and stress before, during and after residential respite found that carers felt as burdened and stressed as before the intervention within two weeks of return to their care responsibility (Neville et al., 2015, p.56). Furthermore, qualitative evidence in line with experience of carers in this study suggests that carers experience difficulties leaving their relative with dementia in facilities that do not agree with carers' expectations of a supportive care environment (Singh et al., 2014, p.6).

Carers in my study and the wider literature uniformly expressed the need for time for themselves in order to maintain and protect their well-being. The available evidence moderately points towards effectiveness and cost-effectiveness of respite services. Examples include reduced stress and burden, improved general health, greater social and recreational opportunities for carers as well as a number of positive outcomes for the care-recipient (Neville et al., 2015, pp.56-57; Ackerman & Sheaffer, 2018, pp.89-90; Vandepitte et al, 2016; Knapp, Iemmi & Romeo, 2012). Yet, uptake of services remains low.

More could be done to design services that address the needs of people with dementia and their carers. In my study and other research, carers emphasised the importance of feeling comfortable with leaving their care-recipient with people the person with dementia felt comfortable with and they could trust (see also Singh et al, 2014). Furthermore, affordability and flexibility in scheduling support are other important aspects that should be considered when designing respite services (Roberts &

Struckmeyer, 2018). Phillipson, Jones and Magee (2014, p.8) additionally suggested the development of programmes that focus on the needs and preferences of specific carer groups in order to increase uptake and acceptability.

8.4.4 Single point of contact to help navigating care services

Related to the issue of finding time for themselves to recover from the relentless responsibility of caring for their relative with dementia, carers highlighted the need for support to help them to navigate the complex and evolving health and social care landscape in their local area. In my qualitative study, several carers expressed their frustration at being pushed around between health and social care providers and, while adjusting to their changing care responsibilities, having to search for services accessible to them. Several carers noted that they would wish for a single point of contact, where they could access information and links to services and where they would not repeatedly have to explain their situation and needs. Even some carers who had established contact with a social worker found it difficult to adjust to high staff turnover.

The need described by participants in my study has also been recognised by policy makers and particularly by third sector organisations, such as the Alzheimer's Society (2019) and Dementia UK (2019). The *Prime Minister's Challenge on Dementia 2009* had already designated GPs and other clinicians to 'have the primary responsibility for commissioning health care, which should ensure that [people with dementia and their carers] get the care that they need and want' (Department of Health, 2009, p.8). While health care clearly is important, a large part of the provision of dementia care services does not necessarily fall directly under the umbrella of health care but in the realm of social care and the voluntary sector.

Over the last few years, interventions have been built up aiming to support people with dementia and their carers in navigating services responding to people's needs. Among these are schemes such as the Admiral Nurses scheme run by Dementia UK in collaboration with the NHS. Admiral Nurses are nurses with special training in dementia care that support people with dementia and their families in dealing with the illness and provide support in finding 'additional care and support' where this is needed (Dementia UK, 2019). In addition, the Alzheimer's Society (commissioned by the government) as well as some mental health trusts and local authorities, run schemes where people with dementia and their carers can access dementia advisers following diagnosis (Ipsos MORI, 2016, p.6). Dementia advisers, sometimes also known as 'Dementia Support Workers, Dementia Care Advisers [or] Dementia Navigators' provide one-to-one support in navigating the care landscape, can support people with

dementia and their carers in seeking advice on health, social care and housing, provide practical advice about the illness and how to deal with some of the challenges, support people in receiving joined-up and person-centred care and in maintaining an active, independent life in the community (Ipsos MORI, 2016, p.7; Alzheimer's Society, 2016, p.7). An evaluation of the dementia adviser scheme has found the programme to be cost-effective, suggesting that for every £1 invested there were almost '£4 worth of benefits' (Alzheimer's Society, 2016, p.1).

These developments are very welcome and qualitative evidence describes the positive impact that a named contact can have on the well-being and quality of life of people with dementia and their carers (Alzheimer's Society, 2016, pp.9-10; Aldridge & Findlay, 2014). Over recent years, the number of Admiral Nurses and Dementia Advisers has increased and access has widened. Dementia UK, for instance, increased the number of Admiral Nurses to 224 by March 2018. This represents an increase of 15 per cent since 2016/17 (Dementia UK, 2018). In their strategy 2017-2020, the organisation declares their aim to increase the number of Admiral Nurses by a further 50 per cent (Dementia UK, 2017). Maintaining the emphasis on enabling every person with dementia and their family carers to have access to a single point of contact that can support them in navigating their individual dementia pathway, respecting and responding to their individual and often complex needs, is likely to go a long way in supporting the well-being and quality of life of family carers of people with dementia. As access to single point contacts for people with dementia and carers are expanding, it will be important to accompany the provision of these services with thorough evaluations to enable their continuous improvement.

8.4.3 Recognising and supporting GPs in their crucial role as facilitators of a dementia diagnosis and enablers of access to care

GPs and other clinicians play crucial roles in enabling access to the system of support, as discussed above. In most cases, GPs are the first port of call for people concerned about their own memory or that of their partner. The Prime Minister's *Challenge on Dementia 2020* and the 2016-17 NHS Mandate additionally gave GPs key responsibilities in providing people with cognitive impairment access to a diagnosis and therefore are potentially crucial enablers of access to care (Department of Health 2016; Alzheimer's Society, 2016, p.4, Department of Health, 2009). In 2014, GPs were even financially incentivised to increase their awareness of dementia and to diagnose and refer people with memory impairment and suspected dementia to memory clinics. This financial incentive of £55 per diagnosed case, which lasted for several months, has

shown an increase from 344,408 diagnoses in March 2014 to 458,562 in August 2018 (Dementia statistics, 2019).

Findings from my qualitative study (Chapter 5) emphasised the importance of GPs not just as facilitators of diagnosis but also as enablers of access to care and support. Samsi and Manthorpe (2014, pp. 2058-2059) describe that 'first service encounters' can be crucial in either creating assurance or sowing doubts in people with dementia and their carers that their questions will be answered and their concerns will be heard. This is consistent with findings from my research where carers who did not experience supportive medical support in finding a diagnosis felt ignored, alone and blocked from accessing care, while those who felt supported gratefully acknowledged the importance of their GPs.

While policy emphasises the role of GPs, there is only limited coverage in the literature investigating people's experience of trying to access care and support when concerned about cognitive impairment and dementia. A study surveying general practitioners found that GPs reported 'time, resources and lack of knowledge' as barriers to supporting carers of people with care needs. Most GPs in the survey (85%) recognised their support of carers as important, but a similar proportion (86%) also stated that 'supporting carers can be difficult' (Greenwood et al., 2010, p. 100).

The role of unpaid care in dementia and the impact of dementia on families has increasingly been recognised by policy makers. In the English system, GPs and other clinicians have been provided, by design, with important responsibilities to provide people with dementia with a diagnosis and through this are gatekeepers to the care pathway that follows. Many people with dementia walk their individual pathway together with their partners, children and friends. GPs and other clinicians need to receive training and support in how to take unpaid carers – provided the person with dementia agrees to this – on board. In addition, further research is necessary to identify how carers of people with dementia can best be supported by GPs and other clinicians.

8.4.5 Coordinated Emergency plans

My thesis, in line with other literature, has shown the increasing importance of spouses providing unpaid care for their partners with dementia. Increasing risk of frailty among spouses who are themselves elderly has also been recognised in the literature (Schoenmaker & Buntinx, 2010; Black et al., 2008). Spouses themselves, as outlined in Chapter 5, are aware of their responsibility for their partner and the risk that their own ailing health may mean that there might be a point where they can no longer provide

support. Two spouses in my qualitative study emphasised their concern about what would happen to their partners should they suddenly become incapacitated.

This issue is not a new concern: organisations such as Carers UK (2019) and the Carers Trust (2015) encourage carers to make emergency plans and to participate in emergency schemes for carers where they exist. Emergency plans can outline information about individuals whom carers would like to take over the caring responsibility in the case of an emergency, but also provide information about the care recipient's needs and preferences. According to Carers UK, a carer's assessment should involve a conversation about emergency situations and carers should be 'offered help to plan for them' (Carers UK, 2019). Carer emergency card schemes can further formalise this situation. Where these schemes exist carers can register and provide their information to the scheme. The carer then receives a card with a code number. Should the carer be involved in an accident the card can be used to identify that the person is a carer for a dependent person and by providing the code number to the emergency carer card scheme provider, the previously recorded emergency plan can be activated (Carers UK, 2019, Carers Trust, 2015).

While Carers UK note that these services in some areas 'are integrated with police, fire and ambulance services, they may not be available in others' (Carers UK, 2019a). In future, it would be important that carer emergency schemes are offered to all carers and that emergency carer card schemes are available across the country.

In addition, it would be helpful if carer emergency schemes would provide scope for carers to identify personal preferences of the person with dementia. This may include a list of items such as the care recipient's favourite blanket, clothes, music, food or toothpaste, and any other things that may contribute to their well-being. Additional information on the person's preferences have been used in other schemes focusing on personalised care. One prominent example is the Butterfly Scheme, which aims to support people with dementia in hospital. As part of the scheme, family and friends can provide information about the person with dementia using a 'see who I am' form that enables care staff to support patients according to their individual needs and preferences (Department of Health, 2015, p.33; Jopling, 2017, p.45). An evaluation of a similar scheme in the Royal Wolverhampton Hospital NHS Trust resulted in positive results regarding the personalised care for patients with dementia and greater satisfaction among patients, their carers and staff (Upton et al., 2012; Brooker et al.,2013; Sullivan, Mannix & Timmons, 2017, p.191). A form similar to the 'see who I am' form as part of emergency planning may help to put carers mind at ease that any replacement care

would be aware of the care recipient's preferences. In addition, it may improve the situation of people with dementia who often are fixated on one carer to better cope with potentially stressful emergency situations that may involve the care recipient with dementia having to leave their safe environment at home.

8.4.6 Support for family members in supporting the main carer and person with dementia

It is widely recognised that dementia of a family member can be disruptive to families (Wexler Sherman, 2012; Peisah, Brodaty & Quadrio, 2006). In my research, consistent with observation in relevant literature, the main responsibility of providing and organising care for a relative is usually taken on by one main carer. The findings of my qualitative study, however, show how important the support of other family members can be for everyone involved. Where families developed effective support strategies, the main carers felt secure and supported. On the other hand, in situations where communication between family members had not been effective, carers reported feelings of disappointment and being unsupported.

Current policies focus solely on one main carer (Care Act, 2014). Carer allowance, for instance, is only provided to family carers providing 35 hours or more hours of care. As outlined above, spouses are one of the main groups of carers, supporting their partners with dementia. However, many carers are frail and elderly themselves and in need of support. This support is often provided by adult children, operating in the background. In other care situations, filial carers often of working age take on the main carer role with support from partners, siblings and their own children. If care policies were reshaped to allow several members of the family to actively participate in the care of their relative, this may improve the current care situation for many families. Potential policy approaches could entail an extension of carer support in the form of staged carer allowance to family members providing care for fewer than the current minimum hours.

A report from Carers UK (2019b) showed that approximately 2 million carers in England had to reduce their work hours due to the intensity of care they provide and 2.6 million carers gave up work in order to provide for their relative with care needs. These findings confirm that many people providing care to a relative incur substantial financial implications through a reduction or loss of income. In addition, the economy loses important members of the labour force.

Establishing employees' rights for flexible working hours could accommodate the active involvement in care by several family members. Adjustable working hours have

been successfully implemented in other countries. For instance, since 2015 employees in Germany have been given the right to take up to 10 days of leave to respond to urgent care needs. During this time employees receive a replacement income. In addition, carers working in companies with more than 15 employees can take up to six months' time out of work to care for a close relative (Bundesministerium der Justiz und für Verbraucherschutz, 2008). Another policy (however, not legally binding for employers) implemented in 2012 enables employees to reduce their work hours to up to 50 per cent for two years. During this time, carers can receive an interest-free loan to cover the reduction in income. This will be paid back over time when the employee resumes full-time work (Bundesministerium der Justiz und für Vebraucherschutz, 2011).

In addition, dementia advisers and support workers could invite relevant family members, as identified by the main carer and the person with dementia, to a moderated exchange about the family care situation. This would enable supportive family members to feel respected and included in the care process, and may enable family members where communication with the person with dementia and the main carer is not so effective to receive information from an independent source. A better understanding of the care needs of the person with dementia, the demands faced by the main carer and understanding of the illness may help to mediate family misunderstandings and conflicts. A family meeting supported by a neutral person aware of the specific situation and knowledgeable of the illness may also help family members to explain their abilities to support the care dyad, especially where this may not reflect the main carer's expectation.

Furthermore, carers in my qualitative study expressed wishes for specific support, such as moments for themselves. While they recognised that others theoretically offered such support, they found constructive and specific offers much more helpful. One husband, for example, described that their niece took care of his wife's hair on a weekly basis. Another husband described the immense benefits he gained from a monthly trip to the pub with his friend, while the friend's wife looked after his wife with dementia. A meeting attended by a professional aware of the needs of people with dementia and their carers may be able to help the main carer voice constructive requests for support.

8.4.7 Further research questions

In addition, the research I conducted as part of this thesis raised a number of further research questions. These are:

- Could the development of a standardised measure with reliable psychometric properties improve the ability to capture and compare carer well-being?

- How could families be supported in providing joint dementia care? Can communication and care management support help to create productive and conducive family environments to support people with dementia?
- Do specific care tasks (the provision of ADLs, IADLs and supervision) have different effects on carers' well-being and quality of life? Could targeted support with these tasks enhance carer well-being and quality of life?

8.5 Limitations and strengths

When I set out to explore differences in well-being and quality of life of men and women of different ages who provide unpaid dementia care to a relative with dementia in the community, I soon learnt that it would be difficult to find population-representative data. As I embarked on the PhD journey, no such dataset existed for England. By using three datasets with slightly different recruitment methods and covering different areas I aimed to address this limitation.

On the other hand, the three datasets START, SHIELD-CSP-RYCT and MODEM enabled me to explore a range of aspects that might influence carer well-being and quality of life due to the detailed information on carers they contained. As outline in Chapter 3.3, MODEM data were collected from 2015 to 2017 and data for START and SHIELD-CSP-RYCT between 2009 to February 2012. The ability to compare three studies that focused especially on carers of people with dementia and that all had been collected in different parts of England within the past nine years were a unique opportunity and strength. Chapter 4 shows that carer characteristics in the datasets used for my research overall sit well with carers aged 50 and older supporting older people with care needs. This suggests that MODEM, START and SHIELD-CSP-RYCT represent well the characteristics of carers for older people.

Government austerity measures affecting social care, however, became more noticeable from 2010. This means that results from START and SHIELD-CSP-RYCT may not accurately reflect the current situation of the well-being and quality of life of carers of people with dementia (Burchardt, Obolenskaya & Vizard, 2016). Both trial datasets were collected in London where support for carers perhaps is more easily accessible than in more rural parts of the country. Similarly, MODEM data were collected in Sussex and may represent a more affluent sample of carers and people with dementia than would have been found in some other parts of the country.

In addition, as with most social sciences, the collection of data depends on the willingness of people to provide information. When it comes to carers of people with dementia, there might be a selection bias through the people agreeing to participate. It is

likely that people who agree to participate in surveys and intervention studies are more likely to be in control and not to be overwhelmed by their care responsibilities. The need for imputation due to loss to follow-up other than death in Chapter 6 suggests that some carers may have become too overwhelmed by the care to be able to continue to participate. Similarly, when recruiting participants for the qualitative study, the main reason why people declined their participation was that they felt overwhelmed by their situation and could not face talking about it to a researcher.

Finally, as voiced by Cohen, Colantonio and Vernich (2002), the longitudinal aspect in care is very important. While in Chapter 6, I explored well-being and quality of life over time, this only amounts to a period of one year, which as stated in Section 6.6 may not have been long enough to observe relevant effects. I decided to limit the period to one year as this study was primarily built around (and funded through) the MODEM project and within the context of the project and this PhD it was only possible to collect data at two time-points. Due to time constraints, it was also not possible to explore factors influencing time spent caring over time (Chapter 7). Other limitations related to the development and analysis of the amended RUD questionnaire used in Chapter 7 can be found in Chapter 3.6.4.

Finally, datasets employed in this thesis, as shown in Chapter 4, contained very limited diversity and do not adequately represent carers of people with dementia from BAME backgrounds. In the care literature it is highlighted that different ethnic and cultural expectations and practices may result in different outcomes for carers (Pinquart & Sörensen, 2005). These potential differences could not be explored in this thesis.

8.6 People's needs are expected to increase, carers require support to maintain their well-being and quality of life

My research investigated the well-being and quality of life of men and women of different age groups and in different relationships to the people with dementia for whom they care. My study emphasised the importance of mental health to the well-being and quality of life of family carers. It further showed that women carry a disproportionate care responsibility throughout life that – coupled with disadvantages in the labour market and resulting socio-economic status – might account for some of the differences observed between men and women. My study further confirmed the increasing importance of older men supporting their wives with dementia and emphasised the importance of getting a better understanding of their experiences and struggles in trying to offer adequate support.

It was estimated that 850,000 people with dementia lived in the UK in 2015. Under the assumption of a stable age-specific prevalence rate this number is set to rise to 'over 1 million by 2025 and over 2 million by 2051' (Prince et al., 2014, p.viii). This increase in the number of people living with dementia is likely be accompanied by an increase in the number of unpaid carers. Already, the value of unpaid care in England amounts to 44.1% of the total cost of dementia (Prince et al., 2014). My research, in line with the wider literature, shows that the provision of time-intensive, personal care for people with dementia can have negative implications on carers' well-being and quality of life. Yet, funding to support people with dementia and their carers has been reduced substantially since 2010, leaving many people struggling (Burchardt, Obolenskaya & Vizard, 2016).

At the same time, the provision of care to vulnerable people, borrowing words from Mascha Madörin (2006, p.283), has been recognised as 'life-sustaining, essential activities, without which societies would not be able to exist and economic growth would be impossible' (translated from German) and therefore is an essential part of human life. Similarly, Deacon (2007, p.483) describes dependency as a 'fundamental part of the human condition'. Across society, the right and duty to care lies overwhelmingly in the private realm of families, with women of all ages and elderly men taking up most care responsibilities. Even though the English government provided some recognition of carers through legislation, such as the Care Act (2014), and despite practice recommendations such as those contained in the recently updated NICE guidelines on dementia (NICE, 2018), more needs to be done to provide support through commitment of additional resources to finance services, which can then enable people with dementia and their carers to maintain and protect their well-being and health-related quality of life.

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Appendix

Appendix 1

Interview guide

This interview guide has been developed to lead the interview. It is not the aim to ask all sub questions, a number of questions have been worded as prompts to explore specific aspects if the interviewee does not touch upon these issues her/himself. Key questions are highlighted in italics. The questions will not necessarily be worded in the same way but the structure of the interview guide will be adhered to in every interview to ensure consistency.

Introduction and context setting

- Introduction of the researcher (name, relation to the study)
- Explanation: focus on the care experience of someone providing unpaid dementia care, and particularly whether there are differences by age and gender
- Study is funded by the Economic and Social Research Council (ESRC)
- The study aims to gain an understanding of how they (as a carer) experience caring for a person with dementia and how they feel this might affect their wellbeing in both good and bad ways.
- During this interview you will ask them some questions and you would like them to tell you about their thoughts and experiences. There are no right or wrong answers. You are interested in their account and opinion.
- The interview will last for a maximum of 90 minutes.
- Confidentiality and anonymity

  You will record the conversation with the help of this recording device so that after the interview you can write down what each of you said. A professional transcription service will transcribe the interviews. The person listening to the interview and typing it on paper will have a signed an agreement of confidentiality and adhere strictly to the Data Protection Act. Transcribing your information is very important because you would like to know exactly what they have said. After this conversation will have been written out you will remove the interviewee's name or any other information that could identify them, or link the data to them. Instead of their name they will be given a code number (with the identifying details kept securely at LSE and not shared with anyone).
- Consent and Withdrawal

  Before you can start with the interview you should ask them if they are happy to sign the consent form. This form states again the process of how you are going to conduct this interview, and what is going to happen with the information provided. By signing this form they agree that you are allowed to use the information they provide during the interview for research.

Of course they can withdraw any time during the interview. Also, if there should be a question they do not feel comfortable in answering; they can just tell you "I would prefer not to answer this question".

- Do they have any questions for you before you start?
- Are they still happy with you going ahead with the interview?

Opening questions/background

- *Would they tell you a little about themselves?*
  - What did they do before starting to look after (name of person with dementia)?
  - Do they currently work (in paid employment, or as a volunteer)?
  - What is their relationship to (name of person with dementia)?
  - When did they start looking after (name of person with dementia)?
  - Did they have a close relationship with (name of person with dementia) before they started caring for him/her?
  - Do they currently experience any health problems themselves?
  - Did they experience those problems before they started looking after (name of person with dementia)?
  - Is (name of person with dementia) the first person they have provided this kind of care to?

Core part of the interview

1. **Care experience**

- *How would they describe their experience of providing dementia care?*

  - Could they tell you about positive aspects of caring? What do they get out of caring? What makes caring rewarding?
  - Could they tell you about aspects of caring they find difficult or stressful?
  - Does (name of person with dementia) show behavioural difficulty or personality changes? How does this affect their caregiving? Do they themselves experience difficult or abusive behaviour from the person they care for (physically/verbally/emotionally)?
  - Does (name of person with dementia) have other conditions/illnesses? Do these other conditions affect the cared-for person's and the carer's daily routine?
  - Do they feel their home environment is suitable for caring? Are there any structural problems, such as the layout of the house, that may make caring or the

life of the person with dementia more difficult? Have they made any changes to the living environment because of the health of the cared-for person?

- Did they have a carer´s assessment? What was the outcome? Did they take up what was offered? Do they have to pay for the services provided?
- Have they ever received training to provide care? If yes, does this help them in their everyday life?
- Do they use technology (such as smart phones, computer (Skype), telecare, baby or similar monitors) to manage looking after (the person with dementia)? How did they come to use these technologies? Do they feel it helps them with their everyday life?

2. Gender aspects

- *What experience in life do they think support their ability to provide dementia care?*

- How do they feel their family and friends view them, now that they are providing unpaid care? Have their emotional bonds to their family or close friends changed since (name of person with dementia) has needed care? How have they changed? Do they feel supported by their family in their roles as a carer for a person with dementia?
- Can they describe how their family and friends support them? Do they feel their network of friends and family has changed since they started caring for (person with dementia)? How do they feel about that?
- How do they feel service providers view their role as carer? Are they happy with the way service providers interact with them?

- *Do they experience gendered stereotypes in their care for (name of person with dementia)? Could they tell you any examples?*

  Explanation: gendered stereotypes are roles or behaviours some people attribute only to men or women.

3. Age aspects

- *How do they think their age affects their caring roles and activities?*

- How do they feel their age affects the type or level of support they receive from friends and family?
- How do they feel their age affects the type of formal support they receive?
- How do they think they would care for (name of person with dementia) if they were ten years younger?

4. Wellbeing

- *Can they describe what they understand by the term wellbeing?*
  - When was the last time they felt completely well? Can they describe that situation? Do they feel generally well today?
  - Do they feel caring has an impact on their emotional wellbeing? How does it impact their wellbeing?
  - Do they feel caring has an impact on their physical health? How would they describe this impact?
  - If the carer is employed: how do they feel about working and providing care at the same time? Does this affect their relationships to (name of person with dementia) or to other members of the family?
  - Would they say that being a carer for (name of person with dementia) has changed how they feel about themselves? How did it change?
  - Would they say that being a carer affects their ability to interact socially (such as meet friends, go to social events)? Do they sometimes feel isolated or lonely?
  - Have they experienced financial implications as a result of caregiving? If so, could they describe how this came about?
  - For partners/spouses: Does the dementia of their partner affect their intimate/sexual relationship? Do they feel this affects their wellbeing?
  - How do they spend their leisure time?
  - How do they draw the balance between the provision of care and their own needs?
  - Do they feel they could step back from the level of care they provide? Who would pick up the responsibility? What is stopping this happening?

Winding down

- *What advice or information would they give to someone who recently became a carer for a relative with dementia?*
- *Are there any other points they would like to raise?*

Conclusion

- Thank them for their time and for sharing their experience with you. Their information is very valuable to help understand better how gender and age may influence carer wellbeing.
- Just to make sure, all the information they have provided will be anonymized and treated confidentially. If they have any questions, they shouldn't hesitate to contact you at a later date.

- Double check that they are fine with you archiving the transcript of the interview in a safe place, as well as to deposit it with the ESRC. It will be fully anonymized before this happens, which means that there won't be any information in there such as their name or other names they mentioned, or any way to identify them or the person they care for.
- Provide participants with leaflet on the MODEM study, contact details and other potentially useful support information.

End of recording

Appendix 2

Table 2.1: Extraction table carer quality of life

Author, Type of study Country,	**Title**	**Quality of life measure**	**Other carer related measures**	**Measures on care-recipient**
Orgeta et al., 2015 **Cross-sectional** **United Kingdom**	Self and carer perspectives of quality of life in dementia using the QoL-AD	*Quality of life* QoL-AD	*Mental health* General Health Questionnaire (GHQ-28) *Caring related stress* Relative's Stress Scale (RSS)	*Quality of life* QoL-AD *Depression* Cornell Scale of Depression in Dementia *Anxiety* Rating of Anxiety in dementia Scale *Dementia severity* Clinical Dementia Rating (CDR) *Self-rated health* Visual analogue Scale (EQ-VAS) of the EQ-5D <u>Carer rated</u> *ADLs and IADLs abilities* The Bristol Activities of Daily Living Scale *Dementia severity* Clinical Dementia Rating (CDR)
Moreno et al., 2015 **Cross-sectional** **Colombia**	Caregiving in Dementia and its Impact on Psychological Functioning and Health-Related Quality of Life: Findings from a Colombian Sample	Short Form Health Survey (SF36)	*Depression* Patient Health Questionnaire (PHQ-9) *Life Saitsfaction* Satisfaction with Life Scale (SWLS) *Burden* Zarit Burden Interview	
Gaugler et al., 2015 **Single-blind randomized controlled trial** **United States**	Effects of the Minnesota Adaptation of the NYU Caregiver Intervention on Depressive Symptoms and Quality of Life for Adult Child Caregivers of Persons with	*Quality of life ratings* Cantril ladder	*Depressive symptoms* The Geriatric Depression Scale (GDS) (sub-scales) *Resources:* The Stokes Social Network List *Caregiver satisfaction*	*Care recipient characteristics* Socio-demographic characteristics *Dementia severity* Global Deterioration Scale

	Dementia		Satisfaction with support Number of community-based/ psychosocial services *Subjective stress:* Involuntary aspects of caring role, carers' feeling of emotional and physical fatigue, filial carers' stress appraisal of problem behaviours (RMPBC)	*Behaviour* Revised Memory and Behaviour Problems Checklist (RMBPC) *Health of care recipient* Carer-rated measure of person with dementia's health
Bleijlevens et al., 2015 **Longitudinal** **8 European countries**	Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study	Health-related quality of life (EQ-5D) *Psychological aspects of quality of life* 12-item General Health Questionnaire (GHQ-12)	*Carer characteristics* Age, gender, marital status, relationship to care-recipient,employment, working hours, number of visits, duration of visits, time spent caring (ADL & IADL in formal care setting) *Hours spent caring* Resource Utilization in Dementia (RUD) instrument *Subjective burden* Zarit Burden Interview (ZBI), Caregiver Reaction assessment (CRA),	
Abdollahpour et al., 2015 **Cross-sectional** **Iran**	Which variable is the strongest adjusted predictor of quality of life in caregivers of patients with dementia?	Single-item question on quality of life	*Carer burden* The Iranian caregiver burden questionnaire (based on Zarit Burden Interview) *Sociodemographics* Age, gender, marital status, relationship to care-recipient, co-residence with care-recipient, years of education	*Dependency* Barthel Index *Dementia severity* Global Deterioration Scale *Sociodemographics* Age, gender, marital status, living situation, residence status, insurance status, number of children, number of carers, years of education
Shuter, Beattie & Edwards, 2014 **Qualitative**	An Exploratory Study of Grief and Health-Related Quality of Life for Caregivers of People with			

Australia	Dementia			
Santos et al., 2014 **Cross-sectional** **Brazil**	Caregivers' quality of life in mild and moderate dementia	Carer's QoL (CQoL) (Brazilian version)	*Burden* Zarit Burden Interview (ZBI) *Depression & Anxiety* Beck Anxiety Inventory (BAI) (Brazilian version)	*Severity* CDR (Brazilian version), MMSE (Brazilian version) *Quality of life* Quality of Life in Alzheimer's disease scale (QoL-AD) (Brazilian version) PQoL/C-PQoL *Functioning* Pfeffer Functional Activities Questionnaires *Depression* Cornell Scale for Depression in Dementia (CSDD) *Behaviour* Neuropsychiatric Inventory (NPI-12) (Brazilian version) Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD)
Papastavrou et al., 2014 **Cross-sectional** **Cyprus**	Factors associated with quality of life among family members of patients with dementia in Cyprus	Quality of Life – Alzheimer's Disease (QoL-AD) (Greek version)	*Burden* Zarit Burden Interview (Greek version) *Depression* Center for Epidemiological Studies-Depression Scale (CES-D) (Greek version) *Functioning* ADL (Greek version) *Carer characteristics* Gender, age, income, education, relationship with the care-recipient, years caring spent caring, support	
Zhang et al., 2014	Self-Efficacy Partially Mediates	Short Form Health Survey	*Carer characteristics* Age, gender,	*Care recipient characteristics*

Cross-sectional **China**	between Socail Support and Health-Related Quality of Life in Family Caregiers for Dementia Patients in Shanghai	(SF-36) (Chinese version)	relationship to care recipient *Social support* Medical Outcomes Study Social Support Survey (MOS-SSS) (Chinese version) *Self-Efficacy* Self-Efficacy Questionnaire for Chinese Family Caregivers (SEQCFC) (Chinese version)	Age, gender *Severity* MMSE *Functioning* Disability Assessment in Dementia (DAD) (Chinese version) *Behaviour* Revised Memory and Behavior Problem Checklist (Chinese version)
Kuo et al., 2014 **Cross-sectional** **Taiwan**	Health-Related Quality of Life and Self-Efficacy of Managing Behavior Problems for Family Caregivers of Vascular Dementia and Alzheimer's Disease Patients	Short Form Health Survey (SF-36) (Taiwanese version) *Depression* Center for Epidemiologic Studies Depression Scale (CES-D) (Chinese version)	*Caregiver self-efficacy* Agitation Management Self-Efficacy Scale.	*Dementia severity* MMSE (Taiwanese version); Clinical Dementia Rating (CDR) *Self-Care Ability* Barthel Index (ADL); Lawton and Brody (IADL) (Chinese version) *Behaviour* CMAI (Chinese version)
Kuo et al., 2013 **Single-blinded randomized clinical trial** **Taiwan**	A home-based training program improves Taiwanese family caregivers' quality of life and decreases their risk for depression: a randomized controlled trial	Short Form Health Survey (SF-36) Taiwan version	*Depression:* Center for Epidemiologic Studies Depression Scale (CES-D) (Chinese version) *Preparation for dementia care* Caregiver Preparedness Scale *Carer Competence* Caregivers Competence of Behavioural Problem Management Scale	
Camic, Williams & Meeten, 2011 **Mixed methods** **United Kingdom**	Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study	Quality of life (WHO-QoL BREF)	Anxiety, stress and depression (DASS)	*Cognitive abilities:* Addenbrooke Cognitive Examination (ACE-R) *Mood:* Geriatric Depression Scale (GDS) *Quality of life:* Dementia Quality of Life (Dem-QoL-4)

				Quality of life Quality of life (Dem-QoL-proxy) *Behaviour* Neuropsychiatric Inventory (NPI) *Functioning* Bristol Activities of Daily Living Scale (BADLS)
Bartfay & Bartfay, 2013 **Cross-sectional** **Canada**	Quality-of-Life Outcomes Among Alzheimer's Disease Family Caregivers Following Community-Based Intervention	The QoL-Alzheimer's Disease (QoL-AD)	*Carer characteristics* Gender, relationship to care recipient, education marital status, hours spent caring Information on support group and adult day care participation	
Bruvik et al., 2012 **Baseline, randomized controlled trial** **Norway**	The Quality of Life of People with Dementia and Their Family Carers	QoL-AD (Norwegian version)	*Depression* Geriatric Depression Scale (GDS) *Other characteristics:* Age, gender, education, occupational status,relationship with patient, having a hobby, physical activity *Care commitment* Time spent caring	*Quality of life* QoL-AD *Cognitive function* MMSE *Neuropsychiatric symptoms* Neuropsychiatric inventory (NPI) *Functioning* Physical Self-Maintenance scale (PSMS) Instrumental ADL scale (IADL) Cornell scale for depression in dementia *Carer rated* QoL-AD scale (proxy) (Norwegian version)
Takai et al., 2011 **Cross-sectional** **Japan**	Subjective experiences of family caregivers of patients with dementia as predictive factors of quality of life	World Health Organization Quality of Life (WHO/QOL-26) questionnaire (Japanese version)	*Burnout* The Pines Burnout Measure (BM) *Depression* The Beck Depression Inventory (BDI-II)	*Severity* MMSE *Behaviour* Neuropsychiatric Inventory (NPI) *Severity* Clinical Dementia Rating (CDR)
Kolykhalov et al., 2011	Cholinergic Treatment of	*Burden* RUD		MMSE ADAS-COG

Longi-tudinal **Russia**	Alzheimer's Disease and Its Influence on Health and the Quality of Life of Carers	questionnaire		*Daily activities* DAD scale (Disability Assessment for Dementia) *Behavioural challenges* Neuropsychiatric inventory (NPI)
Duggleby et al., 2011 **Cross-sectional** **Canada**	A mixed methods study of hope, transitions, and quality of life in family caregivers of persons with Alzheimer's disease	Brief version of World Health Organization Quality of Life (WHOQOLBREF)	*Characteristics* Age, gender, marital status, ethnicity, education, occupation, income, and religious affiliation, relationship to person with AD, length of time caring for caring Herth Hope Index (HHI)	*Characteristics* Age, gender, medical diagnosis
Arango-Lasprilla et al., 2010 **Cross-sectional** **Colombia**	Health related quality of life in caregivers of individuals with dementia from Colombia	Short Form Health Survey (SF-36)	*Characteristics* Education, socioeconomic status, gender, age	
Vickrey et al., 2009 **Cross-sectional** **United States**	Development and preliminary evaluation of a quality of life measure targeted at dementia caregivers	Quality of life measure (CGQOL)	*Carer characteristics* Age, marital status, ethnicity, education	*Care recipient charcteristics* Age, marital status, ethnicity, education
Schölzel-Dorenbos et al., 2009 **Cross-sectional** **Netherlands**	Quality of Life and Burden of Spouses of Alzheimer Disease Patients	The Schedule for the Evaluation of Individual Quality of Life (SEIQoL)	*Carer burden* EDIZ, ZBI (short version), SRB	
Inouye et al., 2009 **Cross-sectional** **Brazil**	Perceived quality of life of elderly patients with dementia and family caregivers: evaluation and correlation	*Carer quality of life* Quality of Life Assessment Scale on Alzheimer's disease (CQofL-AD):	*Carer characteristics* Gender, age, marital status, education, kinship degree *Questionnaire Criterio Brazil:* socioeconomic level	*Sociodemographic characteristics* *Care recipient quality of life* Quality of Life Assessment Scale on Alzheimer's disease (PQofL-AD)
Graff et al., 2007	Effects of Community	Dementia Quality of Life Instrument	*Depression* Centre for	*Quality of life* Dementia Quality

Randomized Controlled Trial **Netherlands**	Occupational Therapy on Quality of Life, Mood, and Health Status in Dementia Patients and their Caregivers: A Randomized Controlled Trial	(Dqol)	Epidemiologic Studies Depression Scale (CES-D) *Health status* General Health Questionnaire (GHQ-12) *Carers sense of control over life* Mastery scale *Carer characteristics* Age, sex, education level, relationship to patient	of Life Instrument (Dqol) *Depression* Cornell Scale for Depression (CSD) *Health status* General Health Questionnaire (GHQ-12) *Care recipient characteristics* Age, sex, education level, patient comorbidity, depressive mood, cognition (MMSE), Revised Memory and Behavioural Problems Checklist (RMBPC)
Andrieu et al., 2007 **Cross-sectional** **France**	New Assessment of dependency in demented patients: Impact on the quality of life in informal caregivers	Dartmouth Primary Care Cooperative Information Functional Health Assessment/ World Organization Project of National Colleges and Academics (COOP/WONCA) charts	*Carer characteristics* Age, gender, cohabitation with patient Short Form Health Survey (SF-36) *Depression* Beck Depression Inventory *Psychological burden* Sense of Competence Questionnaire (SCQ)	*Care recipient characteristics* Age, gender *Cognitive functionin* MMSE *Cost* Evaluation of medical costs Qualitative evaluation of functional disability in dementia
Thomas et al., 2006 **Cross-sectional** **France**	Dementia patients caregivers quality of life: the PIXEL study	carers QoL study specific questionnaire	*Carer characteristics* age, sex, relationships, way of life, length of illness, support *Depression* Single question (mini GDS)	*Severity* MMSE *Depression* Cornell's assessment scale for depression in dementia *Functioning* Katz's ADL classification *Behaviour* Cummings's neuropsychological inventory (NPI) Frontal Assessment

				Battery (FAB) *Care recipient quality of life* Rabin's ADRQL scale, Alzheimer's Disease Related Quality of Life
Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006 **Cross-sectional** **Spain**	Impact on Health-Related Quality of Life and Perceived Burden of Informal Caregivers of Individuals with Alzheimer's Disease	*Health-related quality of life* EQ-5D	*Carer and care recipient characteristics* Age, gender, relationship, setting, type of help/support *Functioning* ADLs, Barthel Index *Burden* Zarit Burden Interview *Severity* Clinical Dementia Rating (CDR) *Health* Patient health status	
Belle et al, 2006 **Randomized Controlled Trial** **United States**	Enhancing the Quality of Life of Dementia Caregivers from Different Ethnic or Racial Groups: A randomized Controlled Trial	*Depression* Centre for Epidemiology Studies Depression Scale (CES-D) *Caregiver Burden* Brief Zarit Caregiver Burden Interview *Self-Care* Carers looking after own health *Social support* Received support, satisfaction with support, negative interactions or support *Problem Behaviours* Revised Memory and Behaviour Problem Checklist	*Carer characteristics* Relationship to care recipient, ethnicity	Institutional placement of care-recipients (6-month follow-up)
Argimon et al, 2005 **Longi-tudinal** **Spain**	Health-Related Quality-of-Life of Care-Givers as a Predictor of Nursing-Home Placement of Patients with	Short Form Health Survey (SF-36)	*Carer characteristics* Age, gender, marital status, level of education, living conditions *Support*	

	Dementia		APGAR questionnaire Carer satisfaction with support Care recipient incontinence Challenging behaviour by the care recipient Carer sleep disruption	
Argimon et al., 2004 **Cross-sectional** **Spain**	Health-related quality of life in carers of people with dementia	Short Form Health Survey (SF-36)	*Sociodemographic data* Structured questionnaire	
Coen et al, 2001 **Cross-sectional** **Ireland**	Individual Quality of Life Factors Distinguishing Low-Burden and High Burden Caregivers of Dementia Patients	*Well-being* General Health Questionnaire (GHQ) *Quality of life* SEI-QoL-DW	*Carer characteristics* Gender, age, marital status, relationship to care recipient, living situation, health status, length of caregiving *Burden* Zarit Burden Interview *Social support* Social Support Appraisals Scale	*Care recipient cognition* MMSE *Behaviour* Baumgarten Dementia Behaviour Disturbance (DBD) Scale *Functional status* Blessed-Roth Dementia Scale (DS)
Bell, Araki & Neumann, 2001 **Cross-sectional** **United States**	The Association Between Caregiver Burden and Caregiver Health-Related Quality of Life in Alzheimer Disease	Health utilities (HUI2)	*Health status* Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) *Caregiver burden* Caregiving mastery, health deterioration, social isolation, quality of relationship, work care-related strain *Time spent caring* Time spent providing assistance with personal care, instrumental activities, visiting	*Care-recipient residence* Community vs. institution (carer informed)
Logiudice et al., 1999 **Randomized Controlled Trial** **Australia**	Do Memory Clinic Improve the Quality of Life of Carers? A Randomized Pilot Trial	The psychosocial dimension of the Functional Limitations Profile (FLP)	*Burden* The Family Burden interview *Psychological distress* The General Health Questionnaire (GHQ)	*Cognition* MMSE *Mental disorders* The Cambridge Examination for Mental Disorders in the Elderly

			Experiences of behavioural problems The Memory and Behaviour Problems Checklist (MBPC) *Knowledge of dementia* 10-item questionnaire *Receipt of services* extent and frequency of community services; use of carer groups	(CAMDEX) *Functional ability* ADLs and IADLS <u>Care informed</u> Informant section on CAMDEX *Cognitive decline* Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) *Behavioural* The Clifton Assessment Procedures for Elderly (CAPE), Behavioural Rating score (BRS)

Table 2.2: Extraction table carer well-being

Author, Type of study Country,	**Title**	**Outcome measure well-being and other**	**Covariates**	**Framework**
Koivisto et al., 2016 **Longitudinal** **Finland**	Early psychological intervention does not delay institutioanlization in persons with mild Alzheimer disease and has impact on neither disease progression nor caregivers' well-being: ALSOVA 3-year follow-up	Primary Care recipient institutionalization Secondary *Mental health* Beck Depression Inventory	*Carer orientation of life* Sense of coherence scale *Carer psychological distress* General Health Questionnaire *Care recipient severity* CDR, MMSE *Functioning* The Alzheimer's Disease Coopertive Study – Activities of Daily Living Inventory (ADCS-ADL) *Care recipient behaviour* Neuropsychiatric Inventory *Care recipient quality of life* QoL-AD	
Fauth, Femia & Zarit, 2016 **Cross-sectional** **United States**	Resistiveness to care during assistance with activities of daily living in non-institutionalized persons with dementia: associations with informal caregivers' stress and well-being	*Depression* CES-D *Overload:* Captivity	*Assistance with ADLs* The Katz ADL *Behaviour Problems (Resistiveness to Care)* Record of Behaviour	Stress-process-models
Chenoweth et al., 2016 **Longitudinal (mixed methods – only quantitative methods reported)** **Australia**	Coaching in self-efficacy improves care responses, health and well-being in dementia carers: a pre-post-test/follow-up study	Revised Scale for Caregiver Self-Efficacy Modified version of the Caregiving Hassles Scale The Short Form Health Survey (SF-12)	*Carer characteristics* Age, gender, language background, culture, education level, carer status, support, income, consumption of alcohol and medication	Self-efficacy for caring model
Snyder et al., 2015 **Longitudinal** **United States**	Dementia caregivers' coping strategies and their relationship to health and well-being: The Cache County Study	*Carer anxiety* Beck Anxiety Inventory (BAI) *Carer comorbidity* Health status: medical/health questionnaire, review of	*Carer coping strategies* Ways of Coping Checklist *Carer characteristics* Relationship to care-recipient, contact, interaction *Severity*	Stress-process model

		medications	MMSE; Dementia severity: Clinical Dementia Rating scale sum of boxes (CDR) *Behaviour* Neuropsychiatric inventory (NPI)	
Cheung et al, 2015 **Quasi-experimental pre-post treatment design** **Hong Kong**	Multicomponent intervention on enhancing dementia caregiver well-being and reducing behavioural problems among Hong Kong Chinese: a traditional study based on REACH II	*Mental health* Center for epidemiologic studies-depression scale (CES-D) *Burden* Zarit burden interview (ZBI) *Positive aspects of caregiving* (PAC) *Behaviour* Revised memory and behavioural problem checklist	*Carer characteristics* Age, gender, marital status, education, employment, housing *Risk appraisal measure* *Caregiver bother*	
Kally et al., 2014 **Longitudinal** **United States**	The Savvy Caregiver Program: Impact of an Evidence-Based Intervention on the Well-Being of Ethnically Diverse Caregivers	*Mastery* Caregiver Mastery *Caregiver Competence* *Depression* Patient Health Questionnaire (PHQ-9) *Behaviour* The Revised Memory and Behaviour Problems Checklist, Management of Meaning, Management of Situation	*Carer characteristics* Ethnic origin, gender, age, marital status, education, income, relationship to care-recipient	
Ask et al., 2014 **Cross-sectional** **Norway**	Mental health and well-being in spouses of persons with dementia: the Nord-Trondelag health study	*Life satisfaction* One-item question on life satisfaction *Anxiety and Depression* The Hospital Anxiety and Depression Scale (HADS) CONOR Mental Distress Index	*Carer characteristics* Gender, age, education, income, number of children, spouse age difference, urban/rural, Co-residence *Dementia* Presence/ absence of dementia diagnosis (ICD-10) *Potential mediators and moderators* subjective health, functional impairment in	Stress process model

			daily life, participation in cultural/social activities, receipt of social support, view of life (religiosity), coping, Extraversion Eysenck Personality Questionnaire	
Orgeta & Lo Sterzo, 2013 **Cross-sectional** **United Kingdom**	Assessing mental well-being in family carers of people with dementia using the Warwick-Edinburgh Mental Well-being scale	*Well-being measure* The Warwick-Edinburgh Mental Well-Being Scale	*Anxiety and depression* The Hospital Anxiety and Depression Scale (HADS) *Stress* The Relative´s Stress Scale (RSS) *Physical health* EQ-5D Visual analogue Scale (EQ-VAS) *Coping* The brief version of the Coping Orientations to Problem Experienced Scale (COPE) *Perceived Social Support* Multidimensional Scale of Perceived Social Support (MSPSS)	Stress-coping model
Chiu, Wesson & Sadavoy, 2013 **Quasi-experimental pre-post treatment design** **Canada**	Improving caregiving competence, stress coping, and mental well-being in informal dementia carers	*Depression* Geriatric depression scale *Mastery* Self-mastery scale Role captivity & overload Caregiving competence scale *Burden* Zarit Burden Interview *Coping* Coping inventory	*Carer characteristics* past psychiatric illness, pre-morbid relationship between carer and care-recipient	Use of Pearlin's scale but no direct notion of stress-process model
Quirk et al, 2009 **Cross-sectional** **United Kingdom**	Development of the carer well-being and support (CWS) questionnaire	Carer well-being and support questionnaire	*Demographics*	
Fauth et al., 2012	Caregivers' relationship closeness with the	*Psychological wellbeing* Affect Balance	*Emotional Closeness* of the Care Dyad Relationship	Stress-process model

Longitudinal **United States**	person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being	Scale, Depression Inventory, Mental Health Component of the SF-12 *Caregiver physical health* SF-12	*Carer characteristics* age, years of education, relationship to care-recipient, carer comorbidity *Care recipient characteristics* care-recipient age, gender, type of dementia *Behaviour* Neuropsychiatric Inventory	
Kwak et al., 2011 **Longitudinal** **United States**	The Impact of TCARE® on Service Recommendation, Use and Caregiver Well-being	Service Recommendation, Compliance and Use Caregiver identity discrepancy *Carer Burden* modified Montgomery Borgatta Caregiver Burden Scale *Depression* Center for Epidemiological Studies – Depressive Symptoms Scale (CES-D)	*Carer Characteristics* Gender, age, race, relationship to care-recipient, self-reported health	Caregiver Identity Theory
Holst & Edberg, 2011 **Longitudinal** **Sweden**	Wellbeing among people with dementia and their next of kin over a period of 3 years	*Caregiver burden* *Caregiver satisfaction*	*Carer characteristics* Age, gender, occupation, relation to patient, distance to patient, co-residence *Subjective health* *Coping* The COPE index *Care recipient behaviour* Behaviours difficult to handle *Patient mood*	
Williams et al., 2010 **Randomised Controlled Trial** **United States**	Video-Based Coping Skills (VCS) to Reduce Health Risk and Improve Psychological and Physical Well-being in Alzheimer's Disease Family Caregivers	*Perceived Stress* The Perceived Stress Scale *Anxiety & Anger* Spielberger State-Trait Anxiety Inventory (STAI) *Depression* The Center for	*Carer characteristics* Age, ethnicity, gender, education, family income, relation to care-recipient, co-residence *Personal Mastery* Revised Scale for Caregiving Self-Efficacy (CGSE)	

		Epidemiologic Studies Depression Scale (CES-D) *Hostility* MMPI-based Cook-Medley Hostility Scale *Physical well-being Biomarkers* Stress: Blood pressure, Heart rate during stress Salivary Cortisol:	*Sleep* Pittsburgh Sleep Quality Index (PSQI)	
Schoenmakers, Buntinx & DeLepeleire, 2010a **Meta-analytic review** **Belgium**	Supporting the dementia family caregiver: The effect of home care intervention on general well-being	*Depression* General health questionnaire (GHQ);Center for Epidemiological Studies Depression Scale (CES-D); Beck Depression Inventory; PST-Brief Symptom Inventory *Burden* Zarit Burden Interview; Lawton Subject Burden instrument		Stress-process model FIC conceptual framework
Roscoe et al., 2009 **Cross-sectional** **United States**	Well-Being of Family Caregivers of Persons with Late-Stage Huntington's Disease: Lessons in Stress and Coping	*Life satisfaction* Life Satisfaction Index-Z *Self rated health* Medical Outcomes Study Short Form (SF-36) *Depression* The Center for Epidemiologic Studies-Depression Scale (CES-D)	*Functioning* Katz Index of Independence in Daily Living *Care commitment* Time spent caring *Appraisal* Perceived stressfulness, benefits of caring *Mastery* Mastery Scale *Spirituality* Spiritual Involvement and Beliefs Scale-Revised (SIBS-R) *Social support* Support carers received, satisfaction with support	Stress-process model
Arango Lasprilla et al., 2009 **Cross-**	The effect of dementia patient's physical, cognitive, and emotional/ behavioural	*Life Satisfaction* The Satisfaction with Life Scale *Perceived*	*Carer characteristics* Age, gender, years of education, socio economic status, relationship to care-	

sectional **Columbia**	problems on caregiver well-being: findings from a Spanish-speaking sample from Colombia, South America	*Functional support* The Interpersonal Support Evaluation List (ISEL-12) The Short Health Survey (SF-36) *Depression:* The Patient Health Questionnaire (PHQ-9) *Burden:* The Zarit Burden Interview (ZBI)	recipient *Care commitment* Time spent caring (months; hours/week) *Challenging behaviour* cognitive, emotional/behavioural	
Au et al., 2009 **Cross-sectional** **Hong Kong**	Social support and well-being in dementia family caregivers: The mediating role of self-efficacy	Center for Epidemiologic Studies Depression Scale (CES-D)	*Functioning* The activities of Daily Living Scale (ADL) The MacArthur Social Support Scale Self-Efficacy Scale	Self-efficacy
Charlesworth et al., 2008 **Longitudinal RCT** **United Kingdom**	Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia, and at what cost? A randomised controlled trial	*Carer well-being* Hospital anxiety and depression scale (HADS) *Health-related quality of life* EQ-5D	*Carer characteristics* Age, gender, ethnicity, relationship to care-recipient, hours spent caring, sleep disturbance, other caring roles, employment *Loneliness* Two-item measure of emotional loneliness *Positive and negative affectivity* Positive and Negative Affect Schedule (PANAS) *Burden* Carers Assessment of Difficulties Index (CAD) *Relationship quality* Premorbid relationship; Mutual Communal Behaviours Scale (MCBS), Perceived loss of companionship *Social support* Practitioner Assessment of Network Type (PANT); Multidimensional Scale of Perceived Social Support (MSPSS) *Coping*	

			The Brief Coping Orientation for Problem Experience (COPE) *Live events* List of threatening Experiences *Resource use* Semi-structured interview based on pre-existing interview schedules (CSRI), the Caregiver Time Questionnaire, the Caregiver Activity Schedule (CAS), RUD questionnaire) *Support from family and friends* Questions on regular and occasional support from family and friends	
Tommis et al., 2007 **Cross-sectional** **United Kingdom**	Rural-urban differences in the effects on mental well-being of caring for people with stroke or dementia	*Mental well-being* The Short Form Health Survey (SF-12)	*Carer characteristic* Employment, demographics, health Impact on carer life *Care recipient characteristics* Health, severity, service receipt, unmet needs	
Gitlin et al., 2006 **Cross-sectional** **United States**	Assessing Perceived Change in the Well-being of Family Caregivers: Psychometric Properties of the Perceived Change Index and Response Patterns	Perceived Change Index (PCI)	*Measures of Convergence* Center for Epidemiological Scale of Depression (CES-D), Positive Aspect of Caregiving (PAC) scale, Social Activities Index *Measures of Divergence* MMSE, functional dependence	
Spurlock, 2005 **Cross-sectional** **United States**	Spiritual well-being and caregiver burden in Alzheimer's caregivers	*Spiritual well-being* The Spiritual Well-Being Scale (SWBS) *Carer Burden* The Burden Interview Scale (BIS)	*Carer characteristics* Ethnicity, sex, age, income, education, length of caring, marital status, religiousity, relationship to care-recipient, spiritual or religious behaviours	
Pot et al., 2005 **Longitudinal analysis (1 year)** **United States**	Transitions in Caregivers' Use of Paid Home Help: Associations With Stress Appraisals and Well-Being	*Depression* Center for Epidemiologic Studies Depression Scale (CES-D) *Positive Affect* Positive and	*Caregivers demographics* Gender, relationship to care-recipient, education *Time spent caring* Support with ADLs/IADLs/supervision (paid/unpaid)	Stress process model

		Negative Affect Schedule	*Functioning* ADLs *Behaviour* Revised Memory and Behaviour Problems Checklist *Health* Self-rated health	
McConaghy & Caltabiano, 2005 **Cross-sectional survey** **Australia**	Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being	*Well-being* Satisfaction with Life Scale	*Dementia severity* MMSE score *Carer characteristics* Age, gender, time in caring role, living situation, employment caregiver support, carer education programmes *Mental health* Center for Epidemiological Studies Depression (CES-D); Health status (SF-12) *Burden* Zarit Caregiver Burden Scale *Coping* COPE	
Raina et al., 2004 **Cross-sectional** **Canada**	Understanding the Influence of the Complex Relationships among Informal and Formal Supports on the Well-Being of Caregivers of Persons with Dementia	*Depression* Center for Epidemiologic Studies depression scale (CES-D) *Distress/Burden:* Zarit burden interview *Physical health* self reported health, chronic health issues	*Carer characteristics* age, sex, education, marital status *Care-recipient characteristics* Degree of illness *Functioning* ALDs & IADLs *Behaviour* Dementia behaviour disturbance (DBD) scale *Social networks* Older American Resources and Services project (OARS); carer and care-recipient shared history; social factors; cultural context *Economic factors* Socioeconomic information, access to care	Stress process model
Pinquart & Sörensen, 2004	Associations of caregiver stressors	*Most frequent measures of*	*Functioning* ADLs and IADLs	

Meta-analysis	and uplifts with subjective well-being and depressive mood: a meta-analytic comparison	*subjective well-being* the Positive Affect Subscale of the Affect-Balance-Scale; life-satisfaction scales	*Care recipient severity* MMSE *Care recipient behaviour* Original/revised Memory and Behaviour Problems checklist *Carer commitment* Time spent caring, number of tasks *Measures of perceived uplifts* Perceived gains/ benefits, positive aspects of careing	
Haley et al., 2004 **Cross-sectional** **United States**	Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: findings from the REACH study	*Depression* Center for Epidemiological Studies Depression scale (CES-D) *Anxiety* Spielberger State-Trait Personal Inventory *Caregiver physical health* Likert-scale items	*Carer characteristics* age, sex, marital status, ethnicity, education, employment, income, relationship to care-recipient *Severity* MMSE *Years of Caregiving* Carer report *Caregiving stressors* ADLs and IADLs; Revised Memory and Behaviour Problems Checklist (RMBPC); caregiver appraisal of distress *Appraisals* RMBPC scale; the Behavioural Bother Score; Positive Aspects of Caregiving Scale *Religious coping and behaviour* Likert scale items	
Gaugler et al., 2004 **Longitudinal** **United States**	Family involvement in nursing homes: effects on stress and well-being	*Post-placement subjective stress* Role overload *Post-placement secondary stress* family conflict, interpersonal strain and disagreement (care issues) *Post-placement psychological well-being*	*Nursing home visit* time spent visiting; support with ADLs and IADLs. *Behaviour* problematic behaviour scale *Dementia severity* scale on cognitive impairments *Care needs* ADL and IADLs reliance at	Stress-process model

		Depression the Hopkins Symptoms Checklist	pre-placements *Primary subjective stressors* Pre-placement role overload, role captivity, loss of intimate exchange *Secondary stressors* interpersonal strain and disagreement with family members over care issues *Socio-emotional support* caregivers social networks *Subjective well-being* Depression**:** the Hopkins Symptoms Checklist, guilt *Search issues* finding appropriate nursing home *Nursing home experience* problems with staff, satisfaction with nursing home environment	
Coon et al., 2004 **Cross-sectional** **United States**	Well-being, appraisal, and coping in Latina and Caucasian female dementia caregivers: findings from the REAH study	*Depression* Center for Epidemiological Studies Depression Scale (CES-D) *Well-being:* positive items on CES-D *Anxiety* Spielberger State-Trait Anxiety Inventory *Substance use* Carer self report of psychotropic medication *Carer physical health* Self-perceived health; comparison of health to others; unhealthy behaviour	*Demographic characteristics* Carers age, marital status, ethnicity, education, income, employment status, relationship to care-recipient, occupation *Care-recipient cognition* MMSE *Time spend caring* Years of caring; hours per day *Caregiver stressors* Activities of Daily Living Scale *Behaviour* The Revised Memory and Behaviour Problems Checklist *Appraisals* RMBC's scale; behavioural Bother; The Positive Aspects of Caregiving *Religious coping and behaviour*	

			Acculturation Acculturation Rating Scale for Mexican-Americans-II	
Gaugler et al., 2003 **Case-control-study, longitudinal** **United States**	Adult day service use and reductions in caregiving hours: effects on stress and psychological well-being for dementia caregivers	*Psychological well-being* *Depression* Center for Epidemiologic Studies Depression Scale *Anger* the Hopkins Symptoms Checklist *Primary stressors* behaviour problems scale, ADLs and IADLs, memory problems	*Hours spent caring* Number of hours spent caring *Negative appraisal of primary stress* role captivity, role overload scale, scale on stress and worry *Secondary carer hours* Hours of support from family and friends; hours of paid support	Stress-process model
Chappell & Reid, 2002 **Cross-sectional** **Canada**	Burden and Well-Being Among Caregivers: Examining the Distinction	*Wellbeing* Life Satisfaction Scale *Self- esteem* Rosenberg Self Esteem Scale *Burden* Zarit Caregiver Burden Inventory	*Care-recipient characteristics* Age, gender, martial status, cognitive status, ADL dependence *Behaviour* Behavioural problems *Caregiver characteristics* Age, gender, employment status, education, co-residence, care commitment *Mediator variables* Use of formal services; perceived support; breaks from activity	Burden as distinct from well-being Previously proposed stress/appraisal path model
Rapp & Chao, 2000 **Cross-sectional** **United States**	Appraisals of strain and of gain: effects on psychological wellbeing of caregivers of dementia patients	*Psychological well-being* Positive and Negative Affectivity Scale	*Carer characteristics* Age, gender, ethnicity, education, years as carer, relationship to care-recipient, *Self-rated health* *Stressors* Revised Memory and Behaviour Problem Checklist *Appraisal of strain & gain* Gain: measure developed for study; Strain: abbreviated version of the Revised Caregiver Burden Scale	Two factor model of carer well-being
Harwood et al.,	Predictors of	*Psychological Well-*	*Perceived Emotional*	

2000 **Cross-sectional** **United States**	Appraisal and Psychological Well-Being in Alzheimer's Disease Family Caregivers	*being* Center for Epidemiologic Studies Depression Scale (CES-D) *Caregiver appraisal* Philadelphia Geriatric Center Caregiving Appraisal Scale	*Support* Availability of friends and family scale (PESS) *Physical health* Short-Form Health Survey (SF-36) *Carer characteristics* Age, education, gender, relationship to care recipient, ethnicity *Care recipient behaviour* Behavioural Pathology in Alzheimer's Disease Rating *Severity* MMSE *Functional Impairment* Blessed Dementia Scale *Care recipient characteristics* Age, education, gender, living arrangement	
Coen et al., 1999 **Cross-sectional** **Ireland**	Measuring the Impact on relatives of caring for people with Alzheimer's disease: Quality of life, burden and well-being	*Well-Being* General Health Questionnaire (GHQ-30) *Individual Quality of Life* Schedule for the Evaluation of Individual Quality of Life (SEIQoL-DW)	*Care recipient cognition* mini-neuropsychological investigation (CAMCOG), MMSE *Care recipient behaviour* Baumgarten Dementia Behaviour Disturbance (DBD) scale *Care recipient functional status* abbreviated Blessed-Roth Dementia Scale *Carer burden* Zarit Burden Interview (ZBI) *Carer social support:* Social Support Appraisals (SS-A) Scale	Link to concepts of QoL
Rapp et al., 1998 **Cross-sectional** **United States**	Social resourcefulness: its relationship to social support and wellbeing among caregivers of dementia victims	*Self-rated health:* single item *Quality of life:* single scale *Depression:* Center for Epidemiological Studies Depression scale (CES-D)	*Carer characteristics* carer age, gender, years of caring, relationship to care-recipient *Care-recipient functional status* Revised Memory and Behaviour Problem Checklist (RMBPCL)	Caregiver stress model

		Perceived role benefit score: dichotomous item scale	*Social support and social network size* Perceived social support; Medical Outcome Study Social Support Survey *Social resourcefulness* The Social Resourcefulness Scale (SRS)	

Table 2.3 Overview independent variables used in quality of life studies

	Age	Gender	Education	Ethnicity	Marital status	Children	Language/Culture	Rural/urban	Occupation	Income	Employment	Relationship	Age difference care-recipient	Emotional closeness, dyad	Intimacy	Co-residence	Frequency of contact	Guilt	Burden	Stress	Sleep	Gain/Strain	Health	Mental health	Social resources	Preparedness	Hobby/ cultural activities	Physical activity	Frequency of breaks	Life events	Burnout	Religiousness	Unmet need assistance	Knowledge on dementia	Resistance	Substance use	Coping	Self Esteem	Mastery	Overload/ captivity	Paid help	Carer groups	Informal/ family support	Time spent caring	Institutional visit	Relationship to care staff
Orgeta et al., 2015	X	X	X		X							X				X				X			X	X																		X	X		
Moreno et al., 2015																			X					X																					
Gaugler et al., 2015	X	X	X	X	X	X				X	X									X				X	X															X					
Bleijlevens et al., 2015	X	X			X					X	X	X							X				X		X																		X		
Abdollahpour et al, 2015	X	X	X		X							X				X			X																										
Santos et al., 2014	X	X	X									X							X					X																					
Papastavrou et al., 2014	X	X	X		X	X				X	X	X							X					X																				X		
Zhang et al., 2014	X	X										X													X														X						
Kuo et al., 2014	X	X	X																																			X		X			X		
Kuo et al., 2013	X	X				X						X												X		X																	X		
Camic, Williams & Meeten, 2011																				X				X																					
Bartfay & Bartfay, 2013		X	X		X							X																																X		
Bruvik et al., 2012	X	X	X								X	X												X			X	X																X		
Takai et al., 2011	X	X										X												X						X														
Kolykhalov et al, 2011																			X																								X		
Duggleby et al., 2011	X	X	X	X	X					X	X	X												X							X	X											X		

Total	Logiudice et al., 1999	Bell, Araki & Neumann, 2001	Coen et al., 2001	Argimon et al., 2004	Argimon et al., 2005	Belle et al., 2006	Thomas et al., 2006	Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006	Andrieu et al., 2007	Graff et al., 2007	Inouye et al., 2009	Schölzel-Dorenbos et al, 2009	Vickrey et al., 2009	Arango-Lasprilla et al., 2010	
22	X	X	X	X	X	X		X	X	X	X	X	X	X	Age
23	X	X	X	X	X	X	X	X	X	X	X	X	X	X	Gender
16		X		X	X	X				X	X		X	X	Education
6		X				X							X		Ethnicity
14			X		X	X					X	X	X	X	Marital status
3															Children
0															Language/Culture
0					X										Rural/urban
0															Occupation
6						X					X				Income
7						X								X	Employment
17		X	X			X	X	X		X	X			X	Relationship
0															Age difference care-recipient
0															Emotional closeness, dyad
0															Intimacy
7	X		X	X	X	X			X						Co-residence
0															Frequency of contact
0															Guilt
11	X	X	X					X	X			X			Burden
3															Stress
0															Sleep
0															Gain/Strain
6		X	X						X	X					Health
15	X	X					X		X	X					Mental health
2					X										Social resources
1															Preparedness
1															Hobby/ cultural activities
1															Physical activity
0															Frequency of breaks
0															Life events
1															Burnout
1															Religiousness
2										X					Unmet need assistance
1	X														Knowledge on dementia
0															Resistance
0															Substance use
0															Coping
0															Self Esteem
0															Mastery
0															Overload/ captivity
3	X						X	X							Paid help
0															Carer groups
1		X		X				X							Informal/ family support
14		X	X	X			X						X	X	Time spent caring
0															Institutional visit
0															Relationship to care staff

Table 2.4 Overview independent variables used in well-being studies

	Age	Gender	Education	Ethnicity	Marital status	Children	Language/Culture	Rural/urban	Occupation	Income	Employment	Relationship	Age difference care-recipient	Emotional closeness, dyad	Intimacy	Co-residence	Frequency of contact	Guilt	Burden	Stress	Sleep	Gain/Strain	Health	Mental health	Social resources	Preparedness	Hobby/ cultural activities	Physical activity	Frequency of breaks	Life events	Burnout	Religiousness	Unmet need assistance	Knowledge on dementia	Resistance	Substance use	Coping	Self Esteem/ Efficacy	Mastery	Overload/ captivity	Paid help	Carer groups	Informal/ family support	Time spent caring	Institutional visit	Relationship to care staff
Koivisto et al., 2016																				X																									
Fauth, Femia & Zarit, 2016	X	X		X						X										X														X											
Chenoweth et al., 2016	X	X	X				X				X																								X								X			
Snyder et al., 2015												X					X						X													X									
Cheung et al., 2015	X	X	X		X														X																										
Kally et al.2014	X	X	X	X	X					X		X																																	
Ask et al., 2014	X	X	X			X		X		X			X			X							X		X		X	X				X										X			
Orgeta & Lo Sterzo, 2013	X	X	X	X	X							X								X			X	X	X											X							X		
Chiu, Wesson & Sadavoy, 2013		X										X											X																						
Fauth et al., 2012	X		X									X		X									X																						
Kwak et al., 2011	X	X										X											X																						
Holst & Edberg, 2011	X	X							X			X				X							X																		X		X	X		
Williams et al., 2010	X	X	X	X						X		X				X					X																		X							
Roscoe et al., 2009																				X		X										X						X		X		X	X		

	Age	Gender	Education	Ethnicity	Marital status	Children	Language/Culture	Rural/urban	Occupation	Income	Employment	Relationship	Age difference care-[illegible]	Emotional closeness, dyad	Intimacy	Co-residence	Frequency of contact	Guilt	Burden	Stress	Sleep	Gain/Strain	Health	Mental health	Social resources	Preparedness	Hobby/ cultural activities	Physical activity	Frequency of breaks	Life events	Burnout	Religiousness	Unmet need assistance	Knowledge on dementia	Resistance	Substance use	Coping	Self Esteem/ Efficacy	Mastery	Overload/ captivity	Paid help	Carer groups	Informal/ family support	Time spent caring	Institutional visit	Relationship to care staff
Arango Lasprilla et al., 2009	X	X	X		X							X								X																						X		
Au et al., 2009	X	X	X							X															X												X					X	X		
Charlesworth et al., 2008	X	X		X				X			X	X		X					X		X				X				X							X			X		X	X		
Tommis et al., 2007		X						X			X	X																																
Gitlin et al., 2006	X	X	X	X						X		X										X		X		X																X		
Spurlock, 2005	X	X	X	X	X					X		X																			X										X		
Pot et al., 2005		X	X									X				X							X		X														X		X			
McConaghy & Caltabiano, 2005	X	X									X					X			X				X	X											X				X	X		X		
Raina et al., 2004	X	X	X		X														X				X		X														X		X		X	
Pinquart & Sörensen, 2004																						X																				X		
Haley et al., 2004	X	X	X	X	X					X	X	X								X		X	X	X							X										X		
Gaugler et al., 2004	X		X	X						X	X	X			X	X		X	X	X				X	X													X			X	X	X
Coon et al., 2004	X		X	X	X						X	X								X		X									X										X		
Gaugler et al., 2003	X	X	X	X	X					X	X	X				X				X			X																		X		
Chappell & Reid, 2002	X	X	X								X					X									X		X	X	X			X					X			X		X		

Total	Rapp et al., 1998	Coen et al.. 1999	Rapp & Chao, 2000	Harwood et al., 2001	
26	X	X	X	X	Age
26	X	X	X	X	Gender
20			X	X	Education
13			X	X	Ethnicity
9					Marital status
1					Children
1					Language/Culture
3					Rural/urban
1					Occupation
10					Income
9					Employment
22	X	X	X	X	Relationship
1					Age difference care-recipient
2					Emotional closeness, dyad
1					Intimacy
8					Co-residence
1					Frequency of contact
1					Guilt
7		X	X		Burden
9					Stress
2					Sleep
6			X		Gain/Strain
14			X	X	Health
5					Mental health
11	X	X	X		Social resources
0					Preparedness
3					Hobby/ cultural activities
2					Physical activity
1					Frequency of breaks
1					Life events
0					Burnout
6					Religiousness
0					Unmet need assistance
0					Knowledge on dementia
1					Resistance
1					Substance use
4					Coping
2					Self Esteem/ Efficacy
2					Mastery
1					Overload/ captivity
7					Paid help
1					Carer groups
9				X	Informal/ family support
17	X		X		Time spent caring
2					Institutional visit
1					Relationship to care staff

Table 2.5 Care-recipient variables used in quality of life studies

	Age	Gender	Education	Ethnicity	Marital status	Children	Occupation	Income	Relationship	Living situation	QoL-AD	Depression	Anxiety	Mood	Health status	Comorbidity	ADL/IADLs	Behaviour	Dependency	Severity	Age of onset	Years of illness	Type of dementia	Carers
Orgeta et al., 2015	X	X	X		X					X	X	X	X		X		X			X				
Moreno et al., 2015																								
Gaugler et al., 2015										X					X			X		X				
Bleijlevens et al.., 2015																								
Abdollahpour et al., 2015	X	X	X		X	X				X									X	X				X
Santos et al., 2014	X	X	X		X						X	X					X	X		X	X	X		
Papastavrou et al., 2014																	X							
Zhang et al., 2014	X	X															X			X				
Kuo et al., 2014	X	X															X	X		X				
Kuo et al., 2013																		X						
Camic, Williams & Meeten, 2011											X	X					X			X				
Bruvik et al., 2012	X	X							X		X	X					X			X				
Takai et al., 2011	X	X	X															X		X			X	
Kolykhalov et al., 2011																	X	X		X				
Duggleby et al., 2011	X	X																					X	
Vickrey et al., 2009	X		X	X	X																			
Inouye et al., 2009	X	X	X		X				X		X													
Graff et al., 2007	X	X	X								X	X			X	X		X		X				
Andrieu et al., 2007	X	X	X					X												X				
Serrano-Aguilar, Lopez-Bastida & Yanes-Lopez, 2006	X	X							X								X			X				
Thomas et al., 2006											X						X	X		X				
Belle et al.., 2006	X	X	X														X							
Argimon et al., 2005	X	X	X							X								X		X				
Argimon et al., 2004																						X	X	
Coen et al., 2001																	X	X		X				

	Age	Gender	Education	Ethnicity	Marital status	Children	Occupation	Income	Relationship	Living situation	QoL-AD	Depression	Anxiety	Mood	Health status	Comorbidity	ADL/IADLs	Behaviour	Dependency	Severity	Age of onset	Years of illness	Type of dementia	Carers
Bell, Araki, Neumann, 2001										X														
Logiudice et al., 1999	X	X										X	X				X	X		X				
Total	**12**	**11**	**9**	**1**	**5**	**1**	**0**	**1**	**2**	**4**	**7**	**6**	**2**	**0**	**3**	**1**	**10**	**9**	**1**	**13**	**1**	**2**	**3**	**1**

Table 2.6 Care-recipient variables used in well-being studies

	Age	Gender	Education	Ethnicity	Marital status	Children	Occupation	Income	Relationship	Living situation	QoL-AD	Depression	Anxiety	Mood	Health status	Co-morbidity	ADL/IADLs	Behaviour	Dependency	Severity	Age of onset	Years of illness	Type of dementia	Carers
Koivisto et al., 2016											X						X	X		X				
Fauth, Femia & Zarit, 2016																	X	X		X		X		
Snyder et al., 2015																		X		X				
Ask et al., 2014																	X							
Fauth et al., 2012	X	X																X					X	
Holst & Edberg, 2011	X	X										X		X				X		X				
Roscoe et al., 2009																				X				
Arango Lasprilla et al., 2009															X			X		X				
Au et al., 2009	X	X															X			X				
Charlesworth et al., 2008	X	X		X																				
Tommis et al., 2007															X					X				
Gitlin et al., 2006	X	X															X			X				
Pot et al., 2005																	X	X						
McConaghy & Caltabiano, 2005		X																		X				
Raina et al., 2004															X			X		X				
Pinquart & Sörensen, 2004																	X	X		X				
Haley et al., 2004							X										X	X		X				
Gaugler et al., 2004		X															X	X		X				
Coon et al., 2004																		X		X				
Gaugler et al., 2003																		X						
Chappell & Reid, 2002	X	X			X												X	X		X				
Rapp & Chao, 2000																		X						
Harwood et a., 2001	X	X	X							X							X	X		X				
Coen et al., 1999																	X	X		X				
Rapp et al., 1998																		X						
Total	**7**	**9**	**1**	**1**	**1**	**0**	**1**	**0**	**0**	**1**	**1**	**1**	**0**	**1**	**3**	**0**	**12**	**18**	**0**	**18**	**0**	**1**	**1**	**0**

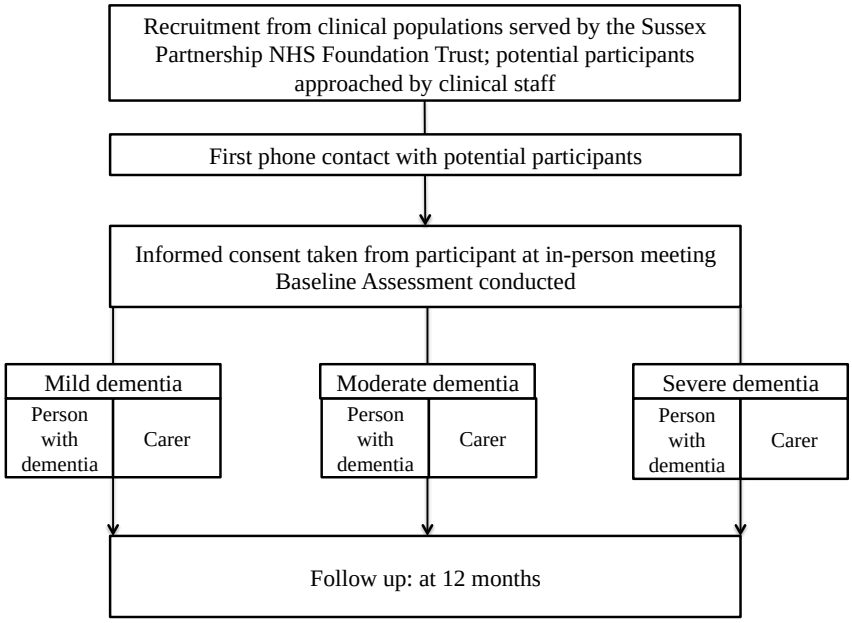
Appendix 3
3.1 Properties of MODEM

The MODEM cohort study drew its participants from the Sussex Partnership NHS Foundation Trust. Clinical staff informed potential participants about the study. Following initial interest researchers contacted potential participants and arranged an in-person meeting.

The baseline interview was conducted following the provision of consent at the first meeting. Based on information from the interview people with dementia and their carers were be classified into the mild, moderate or severe dementia group until 100 carer and person with dementia pairs have been recruited for each dementia severity group. The Carer and the person with dementia were interviewed separately. MODEM included formal and unpaid carers, however, for the purpose of this study only unpaid carers providing care for a person with dementia in the community were considered.

People with dementia participating in MODEM had to have a clinical diagnosis of dementia using ICD-10 criteria. People with dementia were categorised to have mild dementia when scoring 20+ on the standardised Mini-Mental State Examination, moderate dementia with an MMSE score of 10-19 and severe dementia with a score of 0-9. Participants were excluded if no unpaid or formal carer can be identified (Comas-Herrera et al., 2017).

Flow diagram of the MODEM cohort stud



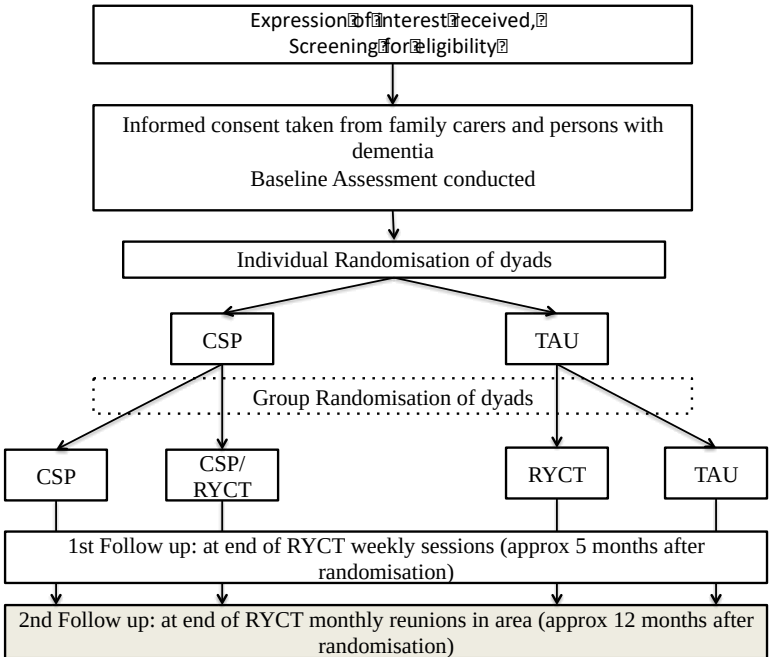
Source: (Comas-Herrera et al., 2017)

3.2 Properties of SHIELD-CSP-RYCT

The SHIELD-CSP-RYCT is a 2×2 factorial single-blinded randomised controlled trial. As illustrated in the flow diagram, a first randomisation into the Carer Supporter Programme (CSP) intervention group and treatment as usual group (TAU) was performed following baseline assessment. The CSP intervention group was then further randomised in a 1:2 proportion into participants receiving the CSP interventions and participants receiving CSP and a group reminiscence intervention (RYCT). Similarly, the TAU group was randomised in a 1:2 proportion into a TAU group and a RYCT group. A 2:1 allocation of participants receiving RYCT in both CSP and TAU arms has been chosen for statistical power. For the purpose of this study only baseline data and data from the 2nd follow-up will be used.

Data was collected from community settings in North East London, Norfolk, Northamptonshire, and Berkshire. CSP-SHIELD–RYCT recruited people with dementia and their unpaid carers from the community by using “leaflets, flyers and posters”, invitations in local papers and newsletters. Participants were also recruited via gatekeepers such as the Alzheimer´s Society and Admiral Nurses. CSP-SHIELD-RYCT excludes people without the ability to speak English. Participation in another study as well as the presence of terminal illness, congenital learning disability or non-progressive brain injury within carer or patient are further reasons for exclusion (Charlesworth et al., 2011).

Flow diagram of the SHIELD CSP-RYCT trial



Source: (Charlesworth et al., 2011, p.2)

Participant of the different study arms receive the following interventions:
Carer Supporter Programme (CSP) The Carer Supporter Programme provides carers' access to an experienced unpaid dementia carer. Care Supporters are being trained for their supporter role before being matched to family carers based on personal preferences, demographic factors and geographical proximity. During the first three months the Carer Supporter is expected to support the family carer for at least on hour on a weekly basis. For the following seven months frequency of contact will be reduced to twice a month. Contact between care supporter and carer can be face-to-face or via telephone. The care supporter is not expected to take over care tasks. A care supporter coordinator supports care supporters throughout the intervention (Charlesworth et al., 2011).

- *Group Reminiscence (Remembering Yesterday, Caring Today)* The 'Remembering Yesterday, Caring Today' (RYCT) group reminiscence programme for people with dementia and their carers' runs for twelve weeks. During a two-hour meeting topics such as 'childhood and family life; school days [or] food and cooking' are being explored through activities such as discussions, singing or acting. An original RYCT programme author has trained all facilitators of the RYCT programme. In four 45-minutes sessions one facilitator will separately work on listening and communication strategies for unpaid carers. Following the 12 weekly sessions monthly reunions for

further seven months have been set up (Charlesworth et al., 2011).

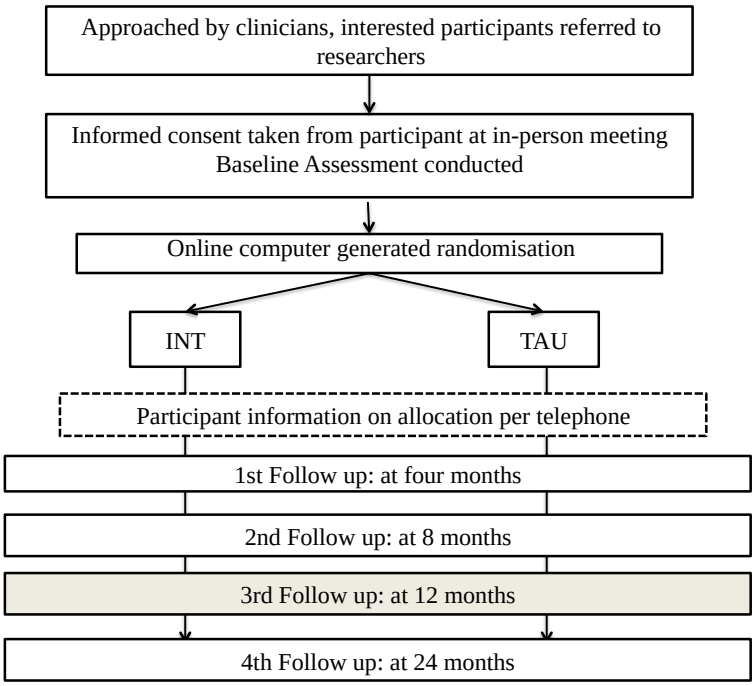
- Combined Intervention (CSP/RYCT) Participants of the combined intervention group are being offered the contact with a care supporter as well as the opportunity to attend the group reminiscence programme. In addition care supporters of participants of the combined intervention have access to RYCT training and a two-hour training of reminiscence techniques. This aims to widen benefits from the RYCT and care supporter intervention (Charlesworth et al., 2011).
- Treatment as usual group: Participants of the TAU group do not receive any of the interventions described above. However, participants can continue with any services they received before or started during the trial.
- All groups:All participants are provided with information of useful resources in their area (Charlesworth et al., 2011).

3.3 Properties of START

The START study is a randomised-controlled trial. All participants in START are carers of people with dementia who have been referred to two mental health and memory services in London and Essex within the last year and reside in the community. Clinicians of the mental health and memory services initially approached potential participants.

As illustrated in the flow diagram participants were interviewed at baseline, prior to allocation into intervention or treatment as usual arm. Baseline data collection happened at the first in-person meeting between participant and researcher, following the provision of informed consent by the participant.

Flow diagram of START trial



Source: (Livingston et al., 2014a)

After computerised randomised allocation with an allocation of 2:1 in the intervention and TAU arms, participants have been informed of their allocation. Follow-up data have been collected at 4, 8, 12 and 24 months. For the purpose of this study, baseline and 12 month follow-up data will be used.

- In START only a distance to the researchers' base of more than 1.5 hours and participation in another study leads to exclusion. Translated versions of measures and interpreters to support the interventions were provided with START (Livingston et al., 2014a). *Participants in the intervention group* Participants of the intervention arm received eight therapy sessions based on the "Coping with Caregiving programme" developed in the United States but adapted for the UK context. The intervention provided carers with information about dementia, the experience of carer stress and a better understanding of behaviour of the person with dementia. This was facilitated with the help of discussions of the topics, learning of management techniques, self-caring skills, relaxation, and communication. Participants were also prepared for potential future needs of people with dementia as well as the incorporation of pleasant activities into the caring day. Emphasis was also placed on the maintenance of learned skills over time (Livingston et al., 2014a).

- *Participants in the treatment as usual group* In the treatment as usual group care emphasis was placed on the person with dementia and included ‘assessment, diagnosis, and information; drug treatment; cognitive stimulation therapy; practical support; treatment of neuropsychiatric and cognitive symptoms; and carer support’ as outlined in the clinical guidelines for good dementia care by NICE (Livingston et al., 2014a, p.13).

The START study is a randomised-controlled trial. Participants were drawn from mental health and memory services in London and Essex. Participants were interviewed at baseline and at two time points after randomisation. Participants were grouped into an intervention and treatment as usual arm (TAU) with an allocation of 2:1. Participants enrolled in the intervention arm received eight therapy sessions of the ‘Coping with Caregiving programme’ developed in the United States but adapted for the UK context. Participants of the TAU group received no specific intervention but had access to care in line with the clinical guidelines for good dementia care by the National Health Institute for Health and Care Excellence. For the purpose of this study, baseline and 12 month follow-up data will be used (Livingston et al., 2014a).

Appendix 4

Overview of cut-off points for comparability of variables in the datasets START, SHIELD-CSP-RYCT, MODEM, ELSA (Wave VI) and Census 2011 (England)

Table 4.1 Overview categories of ethnic origin in datasets

	MODEM	**START baseline**	**SHIELD-CSP-RYCT**	**Census 2011**	**ELSA Wave VI**
Questions in original questionnaires	*Choose one option that best describes your ethnic group or background*	*Ethnicity*	*Ethnic Group*	*What is your ethnic group?*	*Can I check, to which of the groups on this card do you consider that [^you/ [^name]] belong?*
'White'	English/ Welsh/ Scottish/ Northern Irish/ British Irish Gypsy or Irish Traveller Any other White	White British White Irish White Other	White British White Irish White Other	English/ Welsh/ Scottish/ Northern Irish/ British Irish Gypsy or Irish Traveller Any other White	White
'Asian or Asian British'	Indian Pakistani Bangladeshi Chinese Any other Asian background White and Asian	Asian or Asian British: Indian Asian or Asian British: Pakistani Asian or Asian British: Bangladeshi Chinese Mixed: White and Asian	Indian Pakistani Other Asian background Chinese White and Asian	Indian Pakistani Bangladeshi Chinese Any other Asian background White and Asian	Asian Asian British
'Black or African or Caribbean or Black British'	African Caribbean Any other Black/ African/ Caribbean background White and Black Caribbean White and Black African	Black or Black British: Caribbean Black or Black British: African Black or Black British: other or mixed Mixed: White and Black Caribbean Mixed: White and Black African	Caribbean African Other black background White and black Caribbean White and black African	African Caribbean Any other Black/ African/ Caribbean background White and Black Caribbean White and Black African	Black Black British
'Other'	Arab Any other ethnic group Any other mixed/multiple ethnic background	Other	Other ethnic group Do not wish to specify Other mixed background	Arab Any other ethnic group Any other mixed/multiple ethnic background	Any other group Mixed ethnic group

Table 4.2: Relationship to care-recipient

	MODEM baseline	**START baseline**	**SHIELD-CSP-RYCT baseline**	**ELSA WAVE VI**	**Census**
Questions in original questionnaires	*To begin with, can you tell me what your relationship to (participant) is?*	*Relationship to care-recipient:*	*Relationship to relative with dementia*	*What relation is this person or people to you?*	*How is person X related to person Y*
Spouse or partner	Spouse/ long term partner	Spouse/ Partner	Spouse Partner or	Spouse or partner	Husband or wife Same-sex civil partner Partner
Filial carer	Son/ daughter	Child Daughter/Son in law	(Adult) child	Parent Parent-in-law	Mother or father
Relative	Sibling Other family Member	Nephew/Niece Grandchild Sibling	Other family	Other relative	Son or daughter Step-child Step-brother or step-sister Grandchild Grandparent
Other	Friend	Friend Other	Other relationship	Friend or neighbour Other	Relation-other Unrelated

Table 4.3: Overview of education qualification categories in datasets

	MODEM baseline	START baseline	SHIELD-CSP-RYCT baseline	Census 2011 (England)	ELSA Wave VI
Question	What is your highest level of education?	Level of education	Highest level of education achieved?	Level of highest qualification	Which of the qualifications on this care [^do you have/ have you obtained since then]?
No qualification	No Qualifications	No qualifications	School leaver (14-16)	10: No academic or professional qualification -	No qualification
Further education	- 0 Level/GCSE/Entry level/ School certificate or equivalent - NVQ level1, Foundation GNVQ, basic skills - NVQ level 2, Intermediate GNVQ, City and Guilds craft, BTEC First/ General diploma, RSA diploma - NVQ level3/ Advanced GNVQ, City and Guilds advanced Craft, ONC, OND BTEC national, RSA advanced diploma or equivalent	O levels A levels or other post O level	School leaver (18) Further education (vocational)	11 Level 1: 1-4 O Levels/CSE/GCSEs (any grades), Entry Level, Foundation Diploma, NVQ level 1, Foundation GNVQ, Basic/Essential Skills Diploma, RSA Diploma 13 Apprenticeship 12 Level 2: 5+ O Level (Passes)/CSEs (Grade 1)/GCSEs (Grades A*-C), School Certificate, 1 A Level/ 2-3 AS Levels/VCEs, Intermediate/Higher Diploma, Welsh Baccalaureate, Intermediate Diploma, NVQ level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First/General 14 Level 3: 2+ A Levels/VCEs, 4+ AS Levels, Higher School Certificate, Progression/Advanced Diploma, Welsh Baccalaureate Advance Diploma, NVQ Level 3; Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma	NVQ1/CSE NVQ2/CCE equiv. o-level NVQ 3/GCE a level Higher education below degree
Higher education,	NVQ level 4, HNC, HND, RSA higher diploma, BTEC Higher levels of equivalent Degree Post-Grad	Degree Post-Grad	Higher education (BSc/BA/ equivalent) Postgrad	15 Level 4+: Degree (BA, BSc), Higher Degree (MA, PhD, PGCE), NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher level, Foundation degree (NI), Professional Qualifications (Teaching, Nursing, Accountancy)	NVQ4/NVQ5/ degree or equivalent
Foreign/Other	Foreign education	Other		16 Other: Vocational/Work-related Qualifications, Foreign Qualifications/ Qualifications gained outside the UK (NI) (Not stated/ level unknown) (England & Wales & Northern Ireland)	Foreign/other

Cohabitation

The variable **carer cohabitation** was dichotomously split into 'yes' and 'no'. The classification 'no' contains situation where the unpaid carer does not live with the person with dementia and there is no principal informal carer available (START, MODEM).

Table 4.4 Overview definition of cohabitation

MODEM (wave I)	"Do you live with (participant)?"
START (baseline)	If the patient has a principal informal carer (unpaid), does this carer live in the same household?
SHIELD-CSP-RYCT	Do you live with the relative (co-resident)?
Census 2011 (England)	NA
ELSA (Wave VI)	[^Does the person/ Do any of the people] you care for live with you?

Marital status

Marital status has been grouped into five categories; these are 'single', 'married or co-habitation', 'divorced or separated', 'widowed' and other. Married and co-habitation have been grouped here as it is assumed that two people living together are likely to look after each other. Also the groups 'separated' and 'divorced' have been grouped as it can be assumed that these people no longer look after their previous partner. These classifications have been applied to both, the unpaid carer and the person with dementia.

Table 4.5 Overview marital status

	MODEM baseline	**START baseline**	**SHIELD-CSP-RYCT baseline**	**ELSA WAVE VI**	**Census 2011**
Questions in original questionnaires	*Are you single, married, widowed, divorced, or separated?*	*Marital status (from a legal perspective)*	*Marital status*	*What is [^your/ Name's] current legal marital status?*	*On 27 March 2011, what is your legal marital or same-sex civil partnership status)*
Single	Single	Single/ unmarried	Single	Single, that is never married	Single (never married/ never civil partnership)
Married/ cohabitation with partner	Married	Married	Married	Married, first and only marriage	Married
	Separated	Living as a common law couple	Civil partner	A civil partner in a legally-recognized Civil Partnership	In a registered same-sex civil partnership
		Separated	Separated	Remarried, second or later marriage	Separated, but still legally in a same-sex civil partnership
			Co-habiting	Spontaneous only – A civil partner and has been married or in another Civil Partnership before	
Divorced or separated	Divorced	Divorced	Divorced	Legally separated	Divorced
				Divorced	Formerly same-sex civil partnership dissolved
				Spontaneous only – Formerly a civil partner, the Civil-Partnership is now legally dissolved	
Widowed	Widowed	Widowed	Widowed	Widowed	Widowed
				Spontaneous only – A surviving civil partner: his/her partner having since died	Surviving partner of a same-sex civil partnership
Other	Not Answered	Other	Other		

Employment status

Carers' employment status has been divided into three categories: 'employed', 'unemployed' and 'economically inactive'.

People classified as employed are in the paid workforce and classified as self-, full- or part-time employed or volunteering. The category unemployed includes all people of working age currently not in employment but able and willing to start work. People classified as economically inactive include retired people, people providing full-time care or declare themselves as 'housewife/husband'. People in this category do not actively look for work.

Table 4.6 Overview employment status

	MODEM baseline	**START baseline**	**SHIELD-CSP-RYCT baseline**	**Census 2011 (England)**	**ELSA WAVE VI**
Questions in original questionnaires	*What is your regular employment status?*	*Work:*	*What is your regular employment status?*	*Last week you were?*	*Which one of these, would you say best describes ^[your/names'] current situation?*
Employed	Paid employment'	'Paid employment'	'Paid employment'	'Economically Active (excluding Full-time Students), in Employment, Employee, Part-time' 'Economically Active (excluding Full-time Students), in Employment, Employee, Full-time' 'Economically Active (excluding Full-time Students), in Employment, Self-employed with employees, Part-time' 'Economically Active (excluding Full-time Students), in Employment, Self-employed with employees, Full-time' 'Economically Active (excluding Full-time Students), in Employment, Self-employed without employees, Part-time' 'Economically Active (excluding Full-time Students), in Employment, Self-employed without employees, Full-time'	'Employed' 'Self-employed' 'Semi-retired'
Economically inactive	'Unemployed' Housewife/ husband' Retired' Full-time carer' Volunteer'	'Unemployed' 'Housewife/ husband' 'Retired' 'Volunteer'	'Unemployed' 'Housewife/ husband' 'Retired' 'Full-time carer' 'Volunteer'	Economically Active (excluding Full-time Students), unemployed, seeking work and ready to start in 2 weeks, and waiting to start a job already obtained and available" Economically inactive, retired Economically inactive, looking after home/family Economically inactive, permanently sick/disabled	'Unemployed' Retired' Permanently sick or disabled ''Looking after home or family'
Other not considered				'Economically inactive, Other' 'Economically Active Full-time students, in Employment, Employee, Part-time' 'Economically Active Full-time Students, in Employment, Employee, Full-time' 'Economically Active Full-time Students, in Employment, self-employed' 'Economically Active Full-time Students, Unemployed, Seeking work and ready to start in 2 weeks, and Waiting to start a job already obtained and available to start within 2 weeks'	'Other answer'

Table 4.7 Housing tenure of carers in MODEM, START, SHIELD-CSP-RYCT, ELSA Wave VI and Census 2011 (England)

	MODEM baseline	**START baseline**	**SHIELD-CSP-RYCT baseline**	**Census 2011 (England)**	**ELSA WAVE VI**
Questions in original questionnaires	*What type of accommodation does (participant) normally live in?*	*What type of accommodation does the patient normally live in?*	*What type of accommodation does the relative normally live in?*	*Does your household own or rent this accommodation?*	*In which of these ways [^does the owner/does the renter rent/ do you/[^name] and [^name] occupy/ does [^name] occupy] this accommodation?*
Owner-occupied	'Owner occupied'	'Owner occupied'	'Owner occupied'	'Owns outright'	'Own it outright'
				'Owns with a mortgage or loan'	'Buying it with the help of a mortgage or loan'
				'Part-owns and part-rents (shared ownership)'	'Pay part rent and part mortgage (shared ownership)'
Rental agreement	'Council rented'	'Council rented'	'Council rented'	'Rents (with or without housing benefit)	'Rent it'
	'Housing association rented'	'Housing association rented'	'Housing association rented'		
	'Private rented'	'Private rented'	'Private rented'		
Other not considered	'Care home (residential/care only)'	'Care home (without nursing care)'		'Lives here rent-free'	'Live here rent free (including rent free with relative/friends)
	'Nursing home'	'Care home (with nursing care)'			
	'Other'	Hospital (awaiting placement)'			
		'Other'			

Table 4.8 Overview self-rated health categories in datasets

MODEM (wave I)	"How do you describe your general state of health?"	Good, very good
		Very poor, poor,
START (baseline)	"In general, would you say your health in is …"	Good, very good, excellent
		Poor, fair,
SHIELD-CSP-RYCT (baseline	"In general would you say your health is:"	Very good, good,
		Fair, poor, very poor
Census 2011 (England)	"How is your health in general?"	Good, very good
		Very bad, bad, fair,
ELSA (Wave VI)	"Now I would like to ask you some questions about your health. Would you say your health is…"	Good, very good, excellent
		Poor, fair,

Appendix 5

5.3 Analysis of START data

Table 5.3.1 Univariate analysis START complete case analysis

Variables	**EQ-5D (12 months)**		**HSQ 12 (12 months)**		**HADS depression (12 months)**	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	164		166		187	
Female		-0.07835		05497**		0.3265**
Carer age	164	-0.0057***	166	-0.008	187	0.0116**
Relationship	164		166		187	
Filial carer		0.1716***		-0.1668		-0.5369**
Other unpaid		0.2542**		-0.5600		-0.7987**
Carer marital status	162		164		185	
Married		0.0105		0.0108		0.0544
Divorced		0.0365		0.6344		0.0944
Widowed		0.0604		0.1677		-0.0668
Carer education	141		143		163	
Further education		0.1044		-0.2817		-0.1608
Higher education		0.0959		0.0572		-0.0970
Carer employment	160		162		183	
Not working		-0.1319**		0.0287		0.1602
Co-residence	164		166		187	
Yes		-0.1487**		0.4466**		0.6675***
Carer health	163		165		186	
Good to excellent		0.2076***		-0.9163***		-0.7554***
MCTS score	164	-0.0182**	166	0.1126**	187	0.0969***
Zarit burden score	164	-0.0021	166	0.0336***	187	0.0294***
HADS anxiety	164	-0.0187***	166	0.1262***	187	0.1005***
HADS depression	164	-0.0278***	166	0.1754***		
COPE active coping	164	-0.0029	166	-0.0075	186	0.1239
COPE denial	163	-0.0715**	165	0.0804	185	0.3323***
COPE self-distraction	164	-0.0178	166	0.1938***	187	0.0999**
COPE substance use	164	0.0196	166	0.1651*	187	0.0646
COPE emotional support	164	-0.0115	166	0.0021	187	0.0186
COPE institutional support	164	0.0088	166	-0.0293	187	0.0172
COPE behavioural disengagement	164	-0.0237	166	0.1759**	187	0.2192***
COPE venting	164	-0.0267*	166	0.2931***	187	0.1803***
COPE positive reframing	164	0.0044	166	-0.0407	197	0.0385
COPE planning	164	0.0048	166	-0.0448	169	0.0228
COPE humor	164	0.0186	166	-0.05331	187	-0.0937**
COPE accepting	164	-0.0121	166	0.0173	187	0.0281
COPE religious coping	163	-0.0324**	165	-0.0284	186	0.0507
COPE self blame	164	-0.0021	166	0.1911**	187	0.1064**
Carer counselling	164		166		187	
Yes		0.0557		0.3935		-0.1176
Carer hospital service (incl. outpatient)	164		166		187	
yes		-0.0643		0.1217		0.1704
Carer incurred cost	164		166		186	
yes		-0.0424		0.2841		0.1527
Other carers	154		156		176	
yes		0.0890*		-0.3783*		-0.4259**
Age care-recipient	164	0.0020	166	-0.0009	187	-0.0228**
Gender care-recipient	164		166		187	
Female		0.0964**		-0.1791		-0.2996*
Variables	**EQ-5D**		**HSQ 12 (12 months)**		**HADS depression (12**	

	(12 months)				months)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Care-recipient marital status	163		165		186	
Married		-0.1986*		0.8539*		0.3953
Divorced		-0.0877		0.6806		0.2944
Widowed		-0.0112		0.6071		-0.2221
Dementia severity	164		166		187	
Mild		0.0214		0.121		0.4274**
Moderate		-0.0598		0.2478**		0.9014***
Time care-recipient can be left alone	100		102		116	
		0.0245		-0.6397*		-0.1867
1 hour to less than 6 hours		0.0230		-0.3765		-0.3092
6 hours to less than 12 hours		0.2757		-1.1923		-0.5302
12 hours to less than 18 hours		0.0545		-0.4256		-0.4218
18 to 24 hours						
Challenging behaviour care-recipient (NPI)	164	-0.0036**	166	0.0172**	187	0.0195***
QoL-AD	163	0.0011	165	-0.0139	196	-0.0191*
Receipt of daycare	164		166		187	
Yes		-0.0089		0.0616		0.1817
Receipt of benefits for care-recipient	164		166		187	
		-0.0352		0.4372		-0.1954
Yes						
Care-recipient receipt of social services	164		166		187	
		0.0248		-0.2194		-0.2276
Yes						
Care-recipient hospitalisation	164		166		187	
Yes		-0.0669		0.4769**		0.2612
Care-recipient use community mental health services	164		166		197	
Yes		0.0345		-0.0638		-0.1009

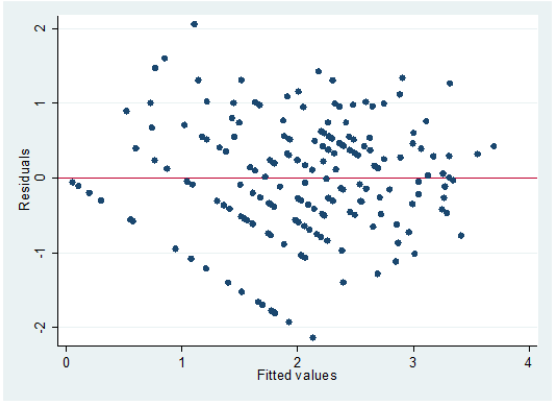
Table 5.3.2 START complete case analysis focusing on carer and care-recipient characteristics

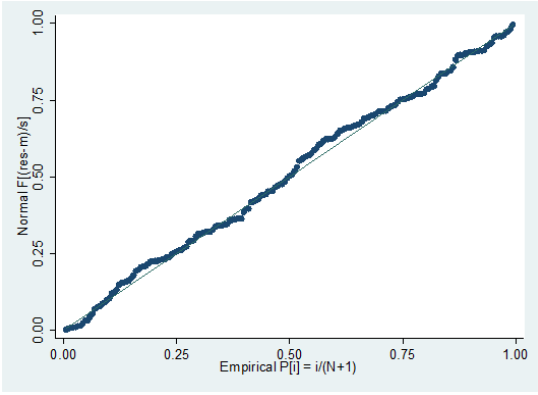
Variables	EQ-5D 12 months		HSQ 12 months		HADS Depression (sqrt) 12 months	
	N=164		N=165		N=187	
	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%
Carer gender						
Female	-0.0568	-0.1534; 0.0397	0.2537	-0.1758; 0.6832	0.2612*	-0.0293; 0.5516
Carer age	-0.0018	-0.0064; 0.0028	0.0007	-0.0197; 0.0211	0.0135*	-0.0003; 0.0273
Relationship						
Filial carer	0.1015	-0.0712; 0.2741	0.0193	-0.7413; 0.7798	0.0768	-0.4325; 0.5860
Other unpaid	0.1735*	-0.0228; 0.3699	-0.1231	-0.9871; 0.7408	-0.3162	-0.8522; 0.2198
Co-residence						
Yes	0.0125	-0.0941; 0.1190	0.2489	-0.2124; 0.7103	0.1476	-0.1767; 0.4719
Age care-recipient	-0.0002	-.0058; 0.0055	0.0034	-0.0213; 0.0282	-0.0199**	-0.0365;-0.0035
Gender care-recipient						
Female	-0.0015	-0.0994; 0.0965	0.0440	-0.3875; 0.4755	0.0794	-0.2196; 0.3784
Dementia severity						
Mild	-0.0227	-0.1259; 0.0807	0.0475	-0.4003; 0.4953	0.2320	-0.0892; 0.5533
Moderate & severe	-0.0965*	-0.2098; 0.0169	0.4379*	-0.0554; 0.9314	0.4536**	0.0965; 0.8107
Baseline score	0.4535***	0.3088; 0.5981	0.4716***	0.3381; 0.6051	0.6372***	0.4982; 0.7761
Randomisation						
Intervention	0.0315	-0.0505; 0.1134	-0.2677	-0.6202; 0.0848	-0.2628**	-0.5092; -0.0163
Constant	0.4612**	0.0210; 0.9013	1.0284	-0.7874; 2.8442	1.0953*	-0.1453; 2.3359

Variables	EQ-5D 12 months	HSQ 12 12 months	HADS D 12 months
	AIC= 7.24	AIC=495.30	AIC=537.29
	R^2=0.3351	R^2=0.3542	R^2=0.4859

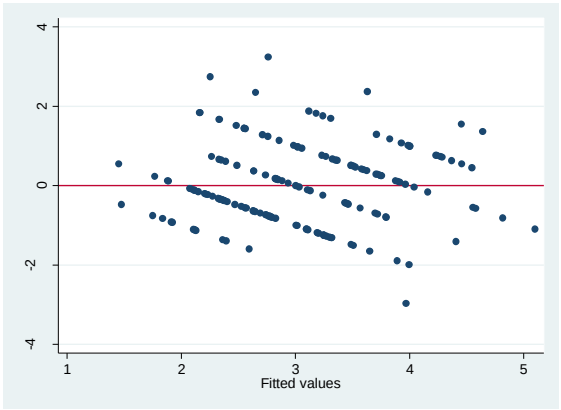
Box 6.3.2 Residuals

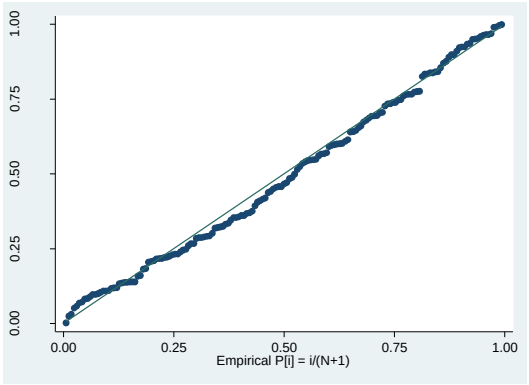
HADS depression



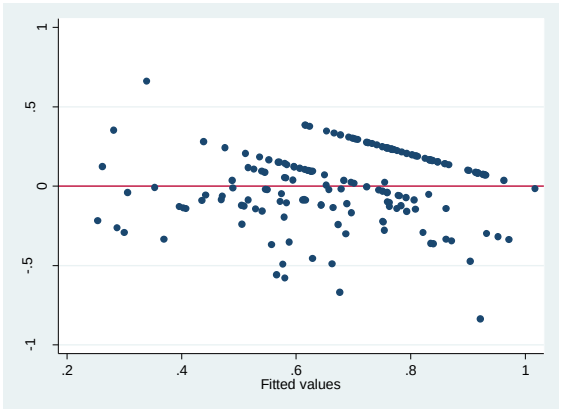


HSQ 12





EQ-5D



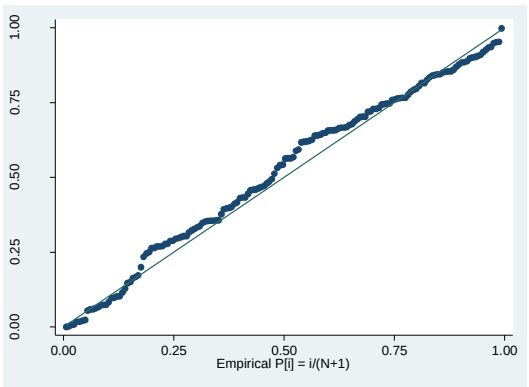


Table 5.3.3 Univariate analysis START imputed analysis

Variables	**EQ-5D (12 months)**		**HSQ (12 months)**		**HADS depression (12 months) (n=20)**	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	241		241		241	
Female		-0.0560		0.4550**		0.3303**
Carer age	241	-0.0047**	241	-0.0021	241	0.0078
Relationship	241		241		241	
Filial carer		0.1362**		-0.0849		-0.4044**
Other unpaid		0.1385*		-0.3455		-0.5508**
Carer marital status	239		239		239	
Married		0.0342		-0.1459		-0.0407
Divorced		0.0498		0.3071		0.0783
Widowed		0.1037		-0.2274		-0.2298
Carer education	241		241		241	
Further education		0.0800		-0.1458		-0.0651
Higher education		0.1013		0.1298		-0.0341
Carer employment	234		234		234	
Not working		-0.1297**		0.0109		0.1483
Co-residence	241		241		241	
Yes		-0.1219**		0.3702*		0.5529***
Carer health	240		240		240	
Good to excellent		0.3219***		-0.7789***		-0.6805***
MCTS score	240	-0.0209**	240	0.0967**	240	0.0948***
Zarit burden score	240	-0.0034**	240	0.0299***	240	0.0269***
HADS anxiety	241	-0.0179***	241	0.1162***	241	0.0979***
HADS depression	241	-0.0261***	241	0.1593***		
COPE active coping	239	-0.0175	239	0.0397	239	0.1026
COPE denial	238	-0.0775***	238	0.1323	238	0.2911***
COPE self-distraction	241	-0.0175	241	0.1438**	241	0.0753**
COPE substance use	241	-0.0009	241	0.1614**	241	0.0995
COPE emotional support	241	-0.0057	241	0.0021	241	0.0227
COPE instrumental support	241	-0.0006	241	-0.0019	241	0.0269
COPE behavioural disengagement	241	-0.0351**	241	0.1552**	241	0.1898**
COPE venting	241	-0.0377**	241	0.2371***	241	0.1714***
COPE positive reframing	241	-0.0030	241	-0.0017	241	0.0443
COPE planning	169	0.0053	169	-0.0484	169	0.0228
COPE humor	241	0.0159	241	-0.0544	241	-0.0913**
COPE accepting	241	-0.0037	241	0.0051	241	0.0019
COPE religious coping	240	-0.0255**	240	-0.0015	240	0.0442
COPE self blame	241	-0.0183	241	0.1650**	241	0.1143**
Carer counselling	241		241		241	
Yes		0.0241		0.4293		0.0329
Carer hospital service (incl. outpatient)	241		241		241	
Yes		-0.0619		0.0464		0.0798
Carer incurred cost	237		227		237	
Yes		-0.0362		0.2521		0.1458
Other carers	241		241		241	
Yes		0.0912*		-0.2840		-0.3452**
Age care-recipient	241	0.0004	241	0.0019	241	-0.0188**
Gender care-recipient	241		241		241	
Female		0.0693		-0.1368		-0.2882**
Care-recipient marital status	240		240		240	
Married		-0.1254		0.6317		0.3427
Divorced		-0.0904		0.6979		0.4239
Widowed		-0.0063		0.4984		-0.0939
Dementia severity	239		239		239	
Mild		-0.0113		0.2590		0.3900**
Moderate		-0.0888		0.6847**		0.7957***

Variables	EQ-5D (12 months)		HSQ (12 months)		HADS depression (12 months) (n=20)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Time care-recipient can be left alone	154		154		154	
1 hour to less than 6 hours		0.0208		-0.4998*		-01922
6 hours to less than 12 hours		0.0172		-0.3261		-0.3472
12 hours to less than 18 hours		0.2805		-0.9956		-0.5395
18 to 24 hours		0.0806		-0.5186		-0.4897*
Challenging behaviour care-recipient (NPI)	241	-0.0040**	241	0.0155**	241	0.0181***
Receipt of daycare	241		241		241	
Yes		-0.0097		0.0843		0.0935
Receipt of benefits for care-recipient	241		241		241	
Yes		0.0014		0.1126		-0.3159
Care-recipient receipt of social services	241		241		241	
Yes		0.0222		-0.1610		-0.340
Care-recipient hospitalisation	241		241		241	
Yes		-0.0494		0.3451*		0.2028
Care-recipient use community mental health services	241		241		241	
Yes		-0.0247		0.1191		0.0201

Table 5.3.4 START imputed analysis focusing on carer and care-recipient characteristics

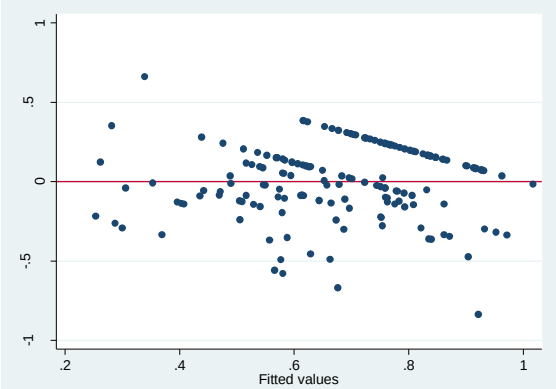
Variables	EQ-5D (sqr) 12 months		HSQ 12 months		HADS Depression (sqrt) 12 months	
	N=239; Imputations=20		N=238; Imputations=20		N=239; Imputations=20	
	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%
Carer gender						
Female	-0.0451	-0.1477; 0.0575	0.2438	-0.1615; 0.6491	0.2116	-0.0620; 0.4852
Carer age	-0.0021	-0.0068; 0.0027	-0.0047	-0.0238; 0.0144	0.0107	-0.0093; 0.0242
Relationship						
Filial carer	0.0696	-0.0971; 0.2363	-0.1359	-0.8979; 0.6260	-0.0215	-0.5159; 0.4728
Other unpaid	0.0664	-0.1309; 0.2637	-0.2569	-1.1565; 0.6427	-0.1949	-0.7049; 0.3149
Co-residence						
Yes	-0.0070	-0.1209; 0.1069	0.3053	-0.1967; 0.8072	0.1610	-0.1413; 0.4634
Age care-recipient	-0.0006	-0.0060; 0.0048	0.0133	-0.0091; 0.0356	-0.0150*	-0.0302; 0.0002
Gender care-recipient						
Female	-0.0113	-0.1059; 0.0833	0.1010	-0.3138; 0.5159	0.1104	-0.1695; 0.3903
Dementia severity	-0.0384	-0.1413; 0.0644	0.1615	-0.2848; 0.6078	0.2035	-0.0947; 0.5017
Mild	-0.0995*	-0.2093; 0.0103	0.4384*	-0.0436; 0.9205	0.3858**	0.0585; 0.7129
Moderate						
Baseline score	0.4763***	0.3333; 0.6239	0.3816***	0.2536; 0.5095	0.6204***	0.4939; 0.7467
Randomisation						
Intervention	0.0346	-0.0528; 0.1220	-0.2082	-0.5609 ; 0.1445	-0.2734**	-0.4998;- 0.0469
Constant	0.4998**	0.0734; 0.9261	0.8867	-0.9360; 2.7095	1.0474*	-0.1192; 2.2139

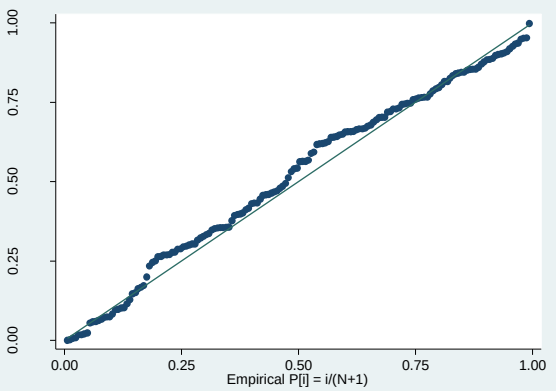
Variables	EQ-5D 12 months (Imputation 0)	GHQ 12 months (Imputation 0)	HADS D 12 months (Imputation 0)
	AIC= 7.2436	AIC=495.30	AIC=447.30
	R^2=0.3351	0.3542	R^2=0.4536

Box 6.3.4 Residuals

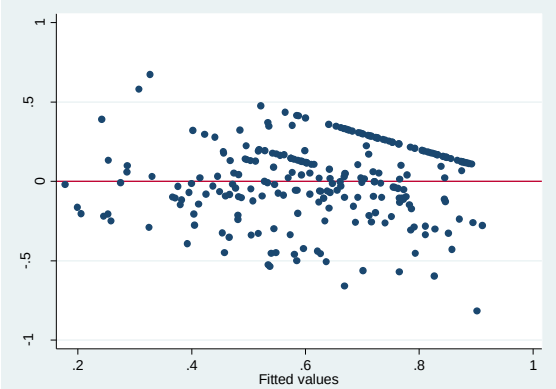
EQ-5D

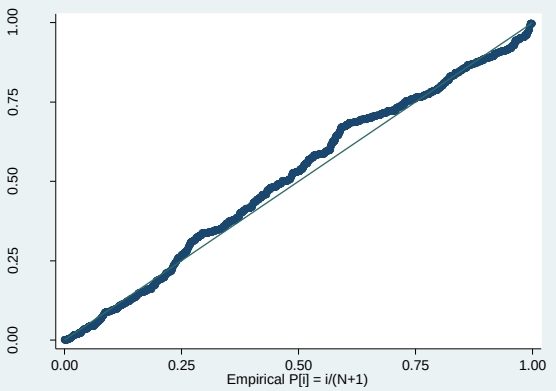
Imputation 0



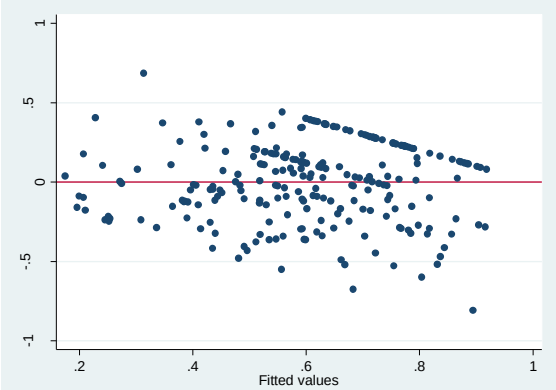


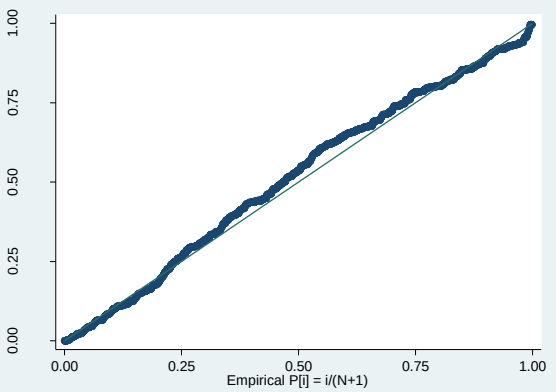
Imputation 4





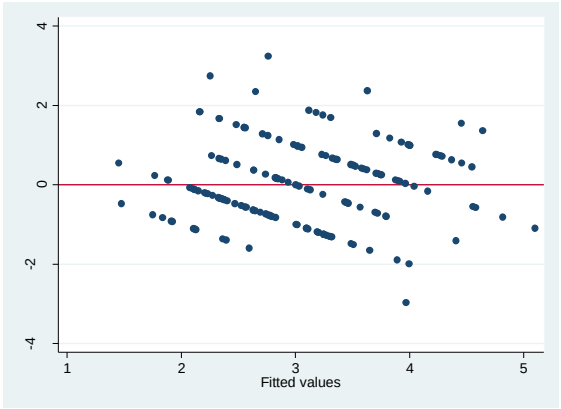
Imputation 15

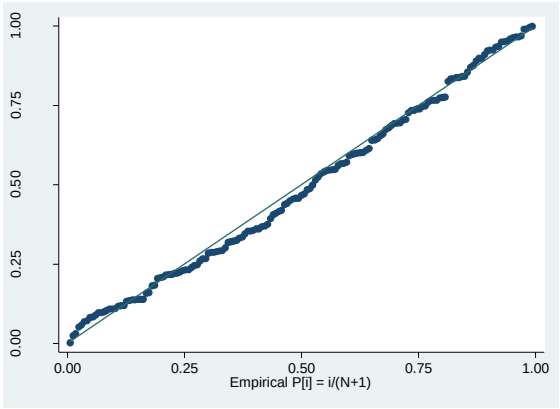




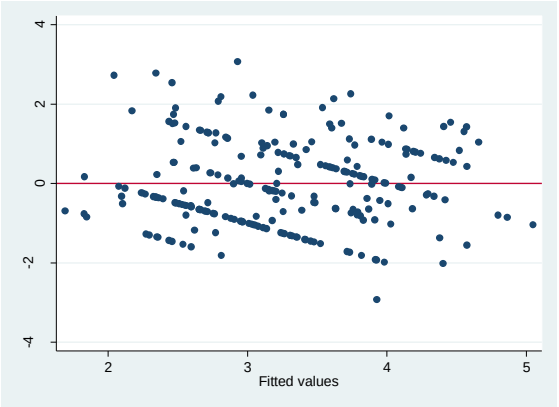
HSQ

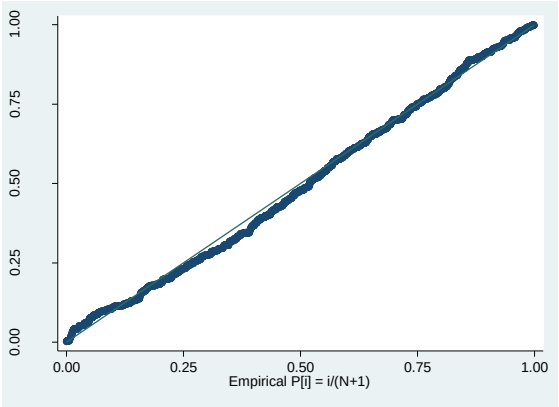
Imputation 0





Imputation 4





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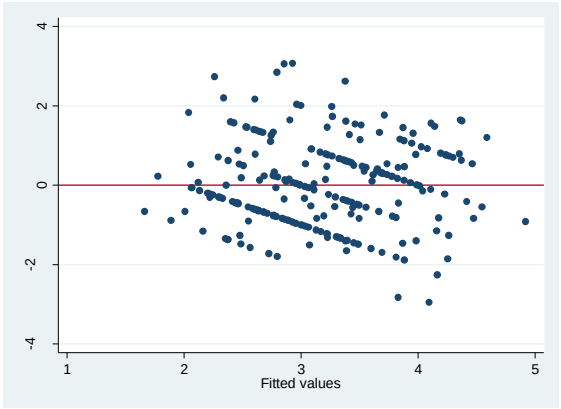
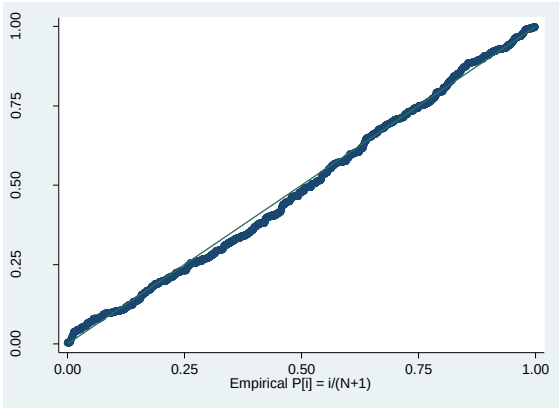
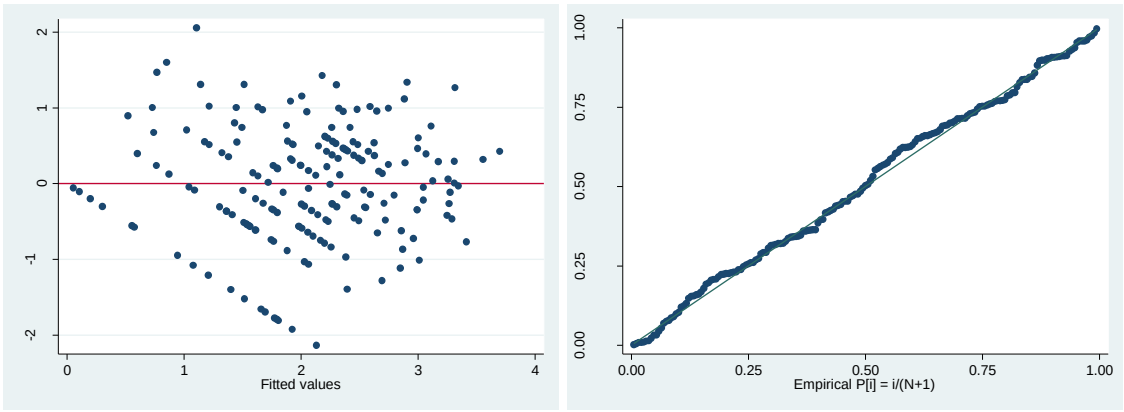




HADS depression

Imputation



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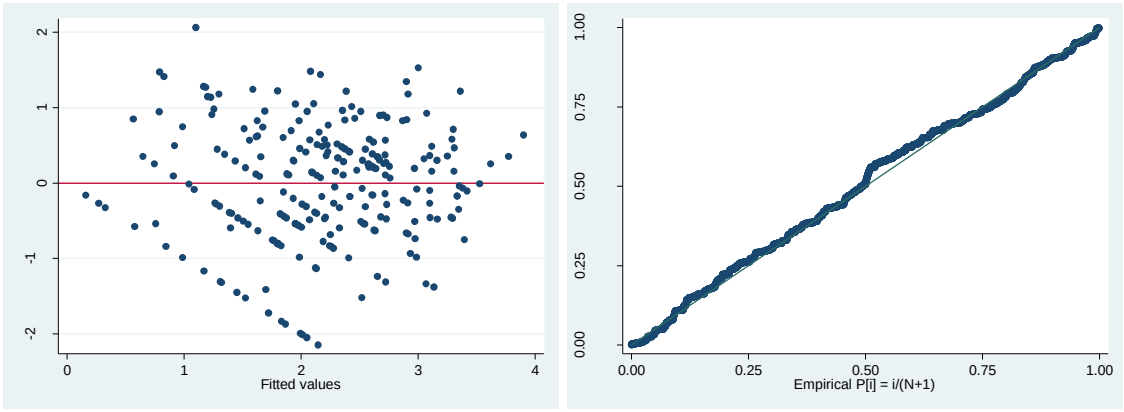
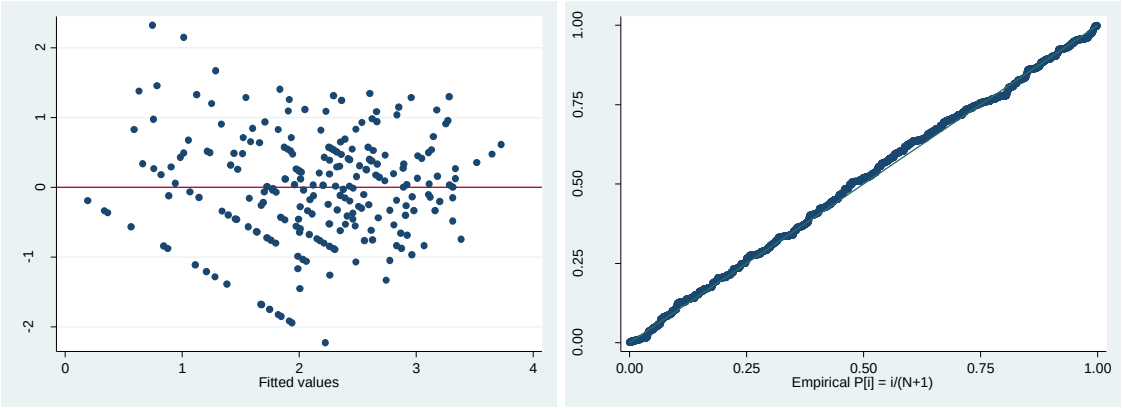


Imputation 15



5.4 Analysis of SHIELD-CSP-RYCT

Table 5.4.1 Univariate analysis SHIELD-CSP-RYCT imputed analysis

Variables	**EQ-5D 12 months**		**HADS depression 12 months**		**PGI 12 months**	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	241		241			
Female		-0.0859**		0.0608	241	-0.3169
Carer age	241	-0.0045	241	0.0048	241	0.0221*
Relationship	241		241		241	
Filial carer		0.1483**		-0.4271**		-0.3886
Other unpaid		0.0257		-0.0964		-0.0467
Carer marital status	241		241		241	
Married		-0.0302		0.0354		-0.6015
Divorced		-0.0785		0.1509		-0.3556
Widowed		0.0754		-0.7506		0.2
Carer education	241		241		241	
Further education		0.0795		-0.03724		-0.3148
Higher education		0.1539**		0.0899		-0.6481
Carer employment	241		241		241	
Not working		-0.1424**		0.1903		0.3171
Co-residence	241		241		241	
Yes		-0.1376**		0.3899**		0.5988*
Time care-recipient can be left alone	178		178		178	-0.3378
6 hours to less than 12 hours		-0.0209		-0.0181		-0.0540
12 hours to less than 18 hours		0.1045		-0.5421**		-2.2458**
18 to 24 hours		0.1057		-0.4038		
Relationship quality (QCQPR)	241	0.0039*	241	-0.01977**	241	0.0138
Obtaining respite (RSSE)	241	0.0005***	241	-0.0018***	241	-0.0007
Responding to disruptive behavior	241	0.0005**	241	-0.0024***	241	0.0013
Controlling upsetting thoughts	241	0.0007***	241	-0.0028***	241	0.0021
HADS anxiety	241	-0.0289***			241	0.0266
HADS depression	241	-0.274***			241	0.0388
Carer physical health (SF12)	241	-0.0181***	241	0.0412***	241	0.0311
Carer mental health (SF12)	241	-0.0228***	241	0.0577***	241	-0.0052
Other carers present	241		241		241	
Yes		0.1001**		-0.1824		-0.4583
Loneliness score	241	-0.0474***	241	0.2105***	241	-0.0762
Age care-recipient	237	-0.0004	237	-0.0102	237	0.0262
Gender care-recipient	239		239		239	
Female		0.0946**		-0.1125		0.1912
Dementia severity	234		234		234	
Mild		-0.1733**		0.1947		-0.0510
Moderate		-0.0759		0.3205		0.5842
Severe		-0.2091**		0.5552*		1.0341
Carer proxy QoL-AD score	241	0.0062*	241	-0.0426***	241	-0.0124
ADCS-ADL total	241	0.0023**	241	-0.0129***	241	-0.0061
Challenging behaviour care-recipient (NPI)	241	-0.0020**	241	0.0132***	241	0.0104
COPE active coping	241	-0.0118	241	0.0236	241	0.1608*
COPE denial	241	-0.0337**	241	0.1239**	241	0.0530
COPE substance use	241	-0.0222	241	0.1445**	241	0.0749
COPE emotional support	241	0.0221*	241	-0.0957**	241	0.0375
COPE institutional support	241	-0.0107	241	0.0139	241	0.1307
COPE behdis	241	-0.0876***	241	0.3979***	241	-0.2483
COPE venting	241	-0.0315**	241	0.1220**	241	-0.0046
COPE positive reframing	241	-0.0146	241	0.0209	241	0.2129**
COPE planning	241	-0.0110	241	0.0475	241	0.0882
COPE humour	241	0.0103	241	-0.0710*	241	0.0794
COPE acceptance	241	0.0151	241	-0.0230	241	-0.0113
COPE religious coping	241	-0.0184*	241	0.0631*	241	0.0583
COPE self-blame	241	-0.0649***	241	0.2995***	241	0.1278

Table 5.4.2 SHIELD-CSP-RYCT imputed analysis focusing on carer and care-recipient characteristics

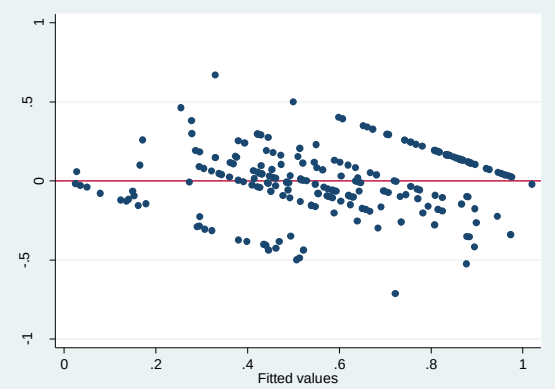
Variables	**EQ-5D 12 months**		**PGI 12 months**		**HADS depression 12 months**	
	N=232; Imputations=5		N=232; Imputation=5		N=232; Imputation=5	
	Coefficient	95%CI	Coefficient	95%CI	Coefficient	95%CI
Carer gender						
Female	-0.0837**	-0.1644; -0.0029	-0.2028	-0.9892; 0.5837	0.1449	-0.1206; 0.4106
Carer age	0.0021	-0.0026; 0.0067	-0.0049	-0.0510; 0.0411	-0.0284***	-0.0440; -0.0127
Relationship						
Child	0.1237	-0.0242; 0.2716	-0.7904	-2.2104; 0.6296	-1.0108***	-1.4921; -0.5294
Other	0.0165	-0.1384; 0.1714	-0.6139	-2.1270; 0.8990	-0.6679**	-1.1830; -0.1529
Co-residence						
Yes	-0.0506	-0.1527; 0.0515	0.6724	-0.2876; 1.6324	-0.0468	-0.3769; 0.2833
Baseline measure	0.7285***	0.6218; 0.8352	0.1486**	0.0607; 0.2366	0.6962***	0.5967; 0.7957
Gender care-recipient						
Female	-0.0283	-0.1103; 0.0536	0.3835	-0.4179; 1.1849	0.1532	-0.1195; 0.4259
Age care-recipient	0.0013	-0.0041; 0.0067	0.0574**	0.0055; 0.1093	0.0107	-0.0071; 0.0285
Dementia severity						
Mild	-0.0961**	-0.1890; -0.0033	-0.1779	-1.0949; 0.7392	0.0032	-0.3055; 0.3118
Moderate	-0.0124	-0.1144; 0.0896	0.5031	-0.5243; 1.5305	-0.0089	-0.3507; 0.3327
Severe	-0.0953	-0.2219; 0.0313	0.8553	-0.3866; 2.0972	-0.0415	-0.4682; 0.3852
Randomisation						
Only CSP	0.0354	-0.0661; 0.1369	-0.1765	-1.1613; 0.8084	0.1119	-0.2192; 0.4431
Only RYCT	-0.0427	-0.1309; 0.0455	0.6869	-0.1846; 1.5585	-0.0294	-0.3257; 0.2669
SHIELD & CSP	-0.0365	-0.1257; 0.0528	-0.0665	-0.9506; 0.8176	-0.0351	-0.3293; 0.2592
Constant	0.0317	-0.3551; 0.4186	5.3045**	1.4783; 9.1308	2.0568**	0.8833; 3.2304

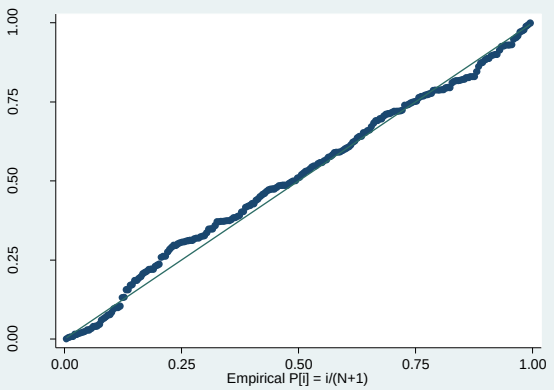
*p≤0.10 **p≤0.05 ***p≤0.01

Box 6.4.2 Residuals

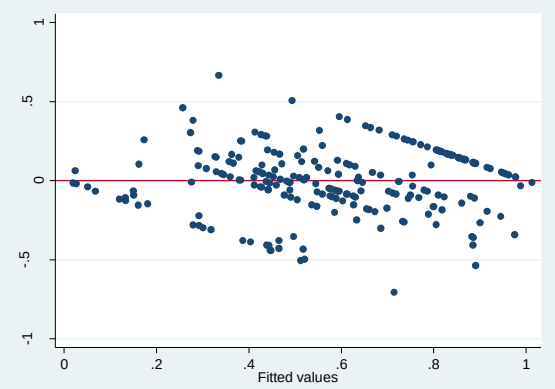
EQ-5D

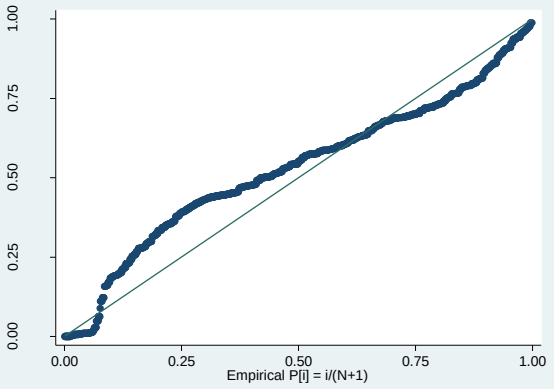
Imputation 0



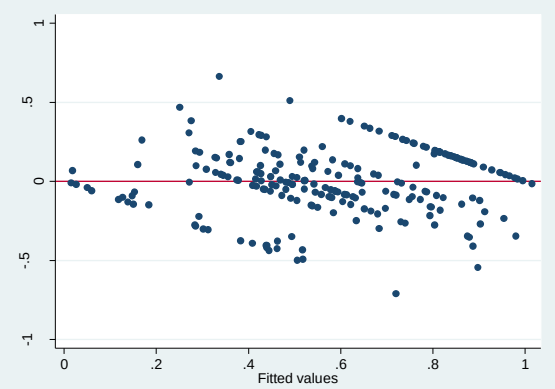


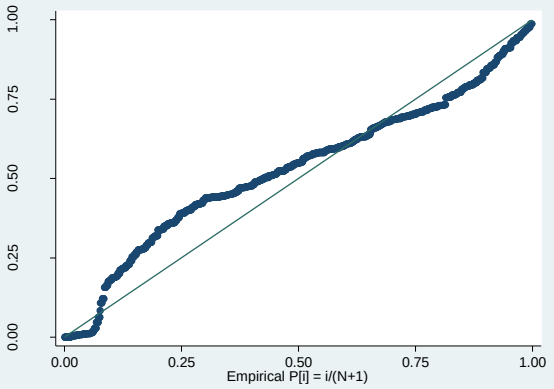
Imputation 1





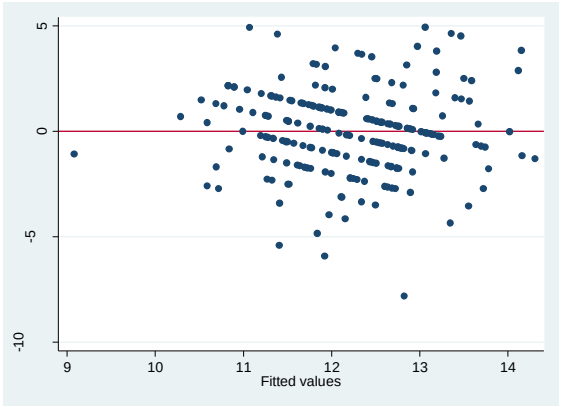
Imputation 4

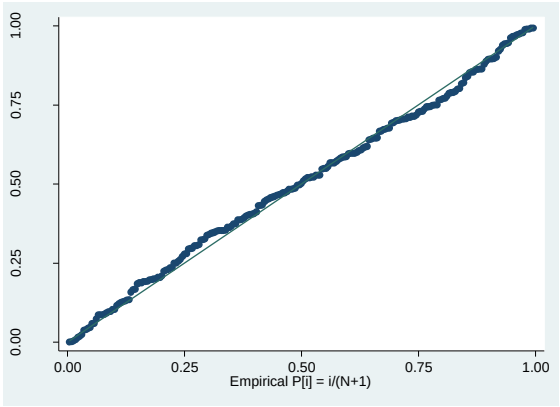




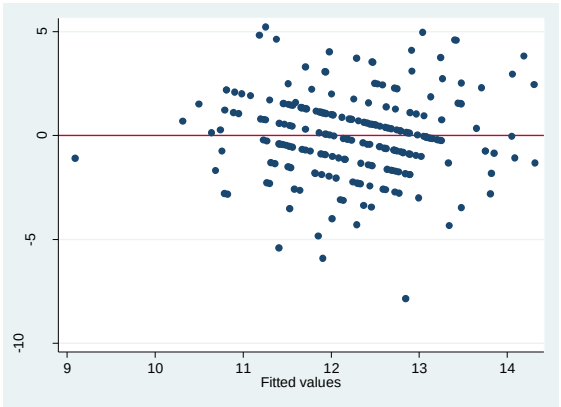
PGI

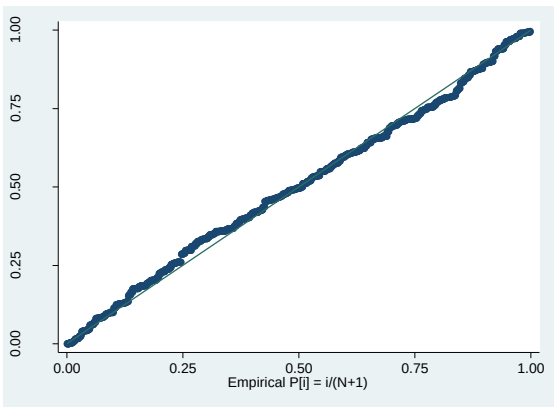
Imputation 0



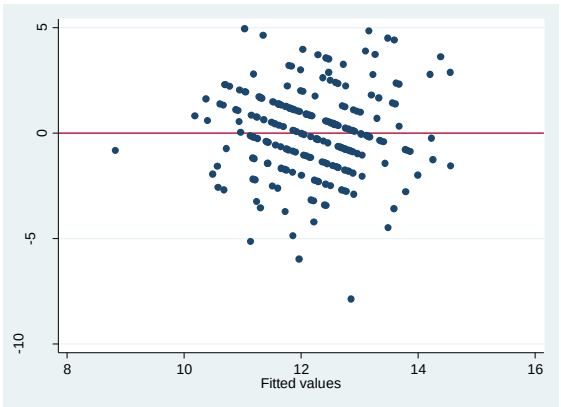


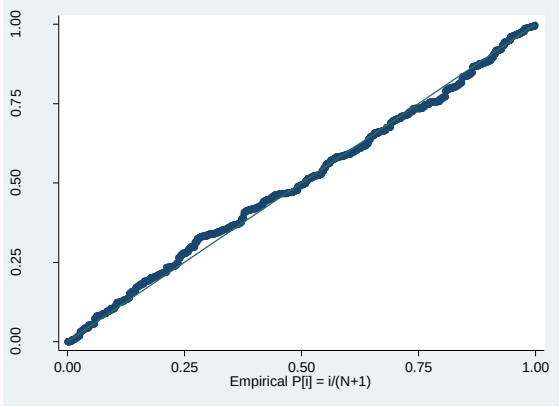
Imputation 1





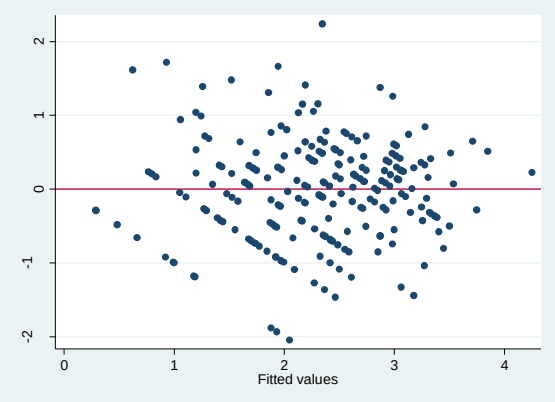
Imputation 4

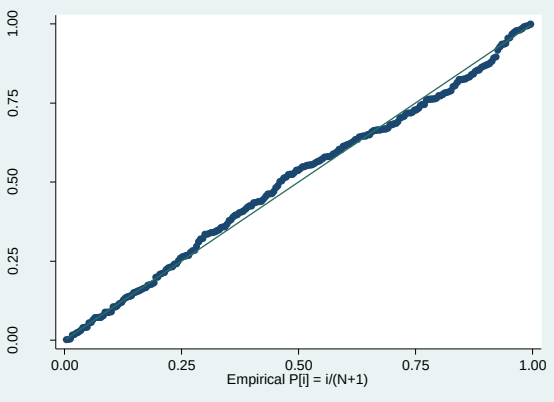




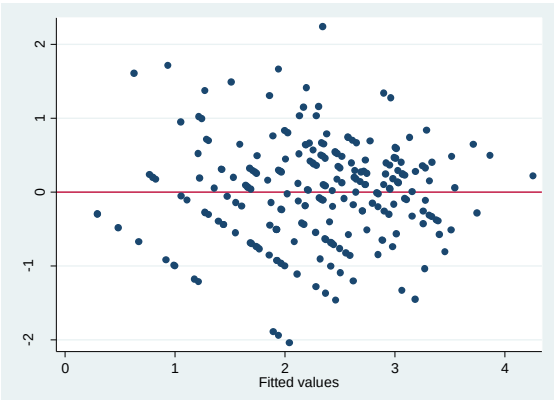
HADS Depression

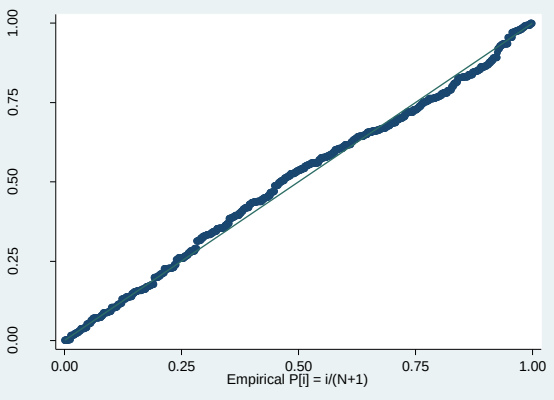
Imputation 0



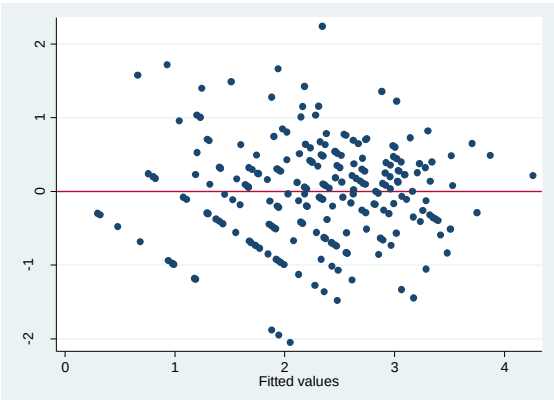


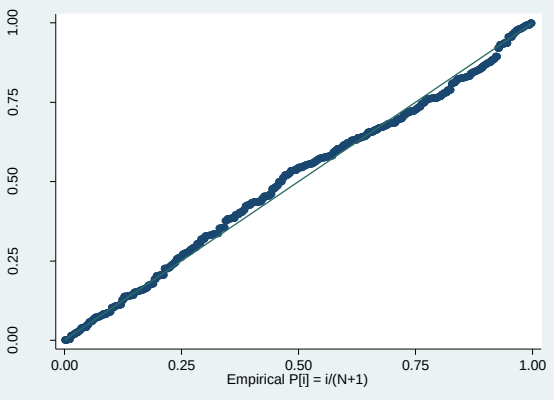
Imputation 1





Imputation 4





5.5 Analysis of MODEM

Table 5.5.1 Univariate analysis MODEM complete case analysis (EQ-5D; GHQ; PWB1)

Variables	**EQ-5D (12 months)**		**GHQ depression (12 months)**		**PWB1 (12 months)**	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	169		171		166	
Female		-0.0015		0.4881**		-8.5403**
Carer age	170	-0.0232	170	-0.0046	165	0.2221
Relationship	170		171		166	
Filial carer		-0.0051		0.2182		0.4479
Other unpaid		-0.1358		-0.0221		13.4688
Carer marital status	160		161		156	
Married		0.1091		-0.1432		0.9137
Divorced		-0.0943		0.5224		-12.3214
Widowed		0.3657		-0.3533		15.25
Carer education	170		171		166	
Further education		-0.0300		-0.0799		-7.3440
Higher education		-0.0278		-0.1734		-3.3313
Other		-0.0824		-0.0305		1.3619
Carer employment	170		171		166	
Not working		-0.0898		-0.0259		3.4759
Co-residence	170		171		166	
Yes		0.0116		-0.4300*		4.2128
Time care-recipient can be left alone	147		148		144	
less than 4 hours		-0.0177		-0.1401		0.4309
4 hours to 8 hours		0.1243		-0.5465*		7.0791
8 to 12 hours		0.1967		-0.3429		-12.8971
12 to 16 hours		-0.1065		-0.2921		5.8529
Sleep-disruption	170		171		166	
Yes		-0.1055**		0.4072**		-6.5758
OARS	164		165		160	
Mildly to moderately impaired social relationships		-0.0178		-0.3230		-1.6733
Severely and totally impaired social relationships		-0.1073*		0.1254		-10.5129*
Zarit burden score	169	-0.0044**	170	0.0367***	165	-0.7966***
Carer health	169		170		165	
Good		-0.1181**		0.4112**		-10.1270**
Poor and very poor		-0.4219***		1.3585***		-28.7056***
Chronic illness	170		171		166	
Yes		-0.2337***		0.5263**		-1.3379
Carer health affected	168		169		164	
Yes		-0.0594		0.7531***		-12.4303**
AGG_MENT	165	0.0041**	166	-0.0531***	161	0.4463**
AGG_PHYS	165	0.0141***	166	-0.0247**	161	0.9255***
Carer counselling	170		171		166	
Yes		-0.2443**		1.2891**		-20.0348**
Carer cash	165		166		162	
Yes		-0.0160		0.3322		2.2348
Carer allowance	164		165		161	
Yes		-0.0638		0.5243**		-12.2559**
Carer community support	170		171		166	
Yes		-0.0162		0.4155**		-4.9787
Other care-recipients	170	-0.0093	171	0.0659	166	-0.3557
Age care-recipient	170	-0.0029	171	0.0038	166	0.3304
Other carers	170		171		166	
Yes		-0.0503		0.1017		-0.9299
Gender care-recipient	170		171	-0.3568**	166	
Female		0.0207				8.7758**

Variables	EQ-5D (12 months)		GHQ depression (12 months)		PWB1 (12 months)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Dementia severity	168		169		164	
Moderate		-0.0541		0.3011		-8.3854**
Severe		0.0352		-0.0240		-0.9039
Challenging behaviour care-recipient (NPI)	160	-0.0026*	161	0.0236***	156	-0.2685**
Variables	**EQ-5D (12 months)**	**GHQ depression (12 months)**	**PWB1 (12 months)**	**EQ-5D (12 months)**	**GHQ depression (12 months)**	**PWB1 (12 months)**
	n	Estimated coefficient	n	n	Estimated coefficient	n
Carer receipient medical services community	170		171		166	
Yes		-0.0367		0.2470		0.6761
Care-recipient hospital	170		171		166	
Yes		0.0175		0.3189*		2.1735
Care-recipient community support	170		171		166	
Yes		-0.1121		0.1364		4.1998
Care-recipient daycare	170		171		166	
Yes		-0.0257		0.3346**		-6.8392*

Table 5.5.2 Univariate analysis MODEM complete case analysis (PWB2; PWB3; PWB4)

Variables	PWB2 (12 months)		PWB3 (12 months)		PWB4 (12 months)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	167		167		167	
Female		-6.8294		-7.9620*		0.4149
Carer age	166	0.1979	166	0.3485*	166	0.0059
Relationship	167		167		167	
Filial carer		-5.5978		-7.0780		-0.7298
Other unpaid		18.0083		31.2856*		-2.3359
Carer marital status	157		157		157	
Married		11.6597		17.0114*		-0.3469
Divorced		-17.8889		-1.6667		-1.9841
Widowed		11.1111		42.3333**		-3.5556
Carer education	167		167		167	
Further education		-4.7228		-14.3474**		0.2157
Higher education		-2.3778		-10.8861*		-0.2715
Other		0.8976		-8.8761		0.0609
Carer employment	167		167		167	
Not working		6.1094		3.4561		0.3679
Co-residence	167		167		167	
Yes		4.3939		5.1862		0.6778
Time care-recipient can be left alone	145		145		145	
		-10.4261*		-1.0451		-0.8786
less than 4 hours		-5.6688		8.6509		-1.0434
4 hours to 8 hours		-7.5735		-20.8015		-0.3529
8 to 12 hours		-8.1985		12.3235		0.1471
12 to 16 hours						
Sleep-disruption	167		167		167	
yes		-4.4999		-4.7994		0.1372
OARS	161		161		161	
Mildly to moderately impaired social relationships		-0.2926		-4.3462		0.4274
Severely and totally impaired social relationships		-9.1563		-12.7620**		1.2428
Zarit burden score	166	-0.8116***	166	-0.8469***	166	0.0660***

Variables	PWB2 (12 months)		PWB3 (12 months)		PWB4 (12 months)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer health	166		166		166	
Good		-5.8217		-10.0712**		1.3588**
Poor and very poor		-29.3259***		-27.3296***		1.975**
Chronic illness	167		167		167	
yes		-8.4144**		-7.4519*		0.7582
Carer health affected	165		165		165	
yes		-10.1156**		-12.3964**		1.0891**
AGG_MENT	162	0.8214***	162	1.0761***	162	-0.1151***
AGG_PHYS	162	0.5899**	162	0.3588*	162	-0.0207
Carer counselling	167		167		167	
Yes		-16.2807*		-22.1470**		1.5495
Carer cash	163		163		163	
yes		-5.8540		-8.8353		-0.4803
Carer allowance	162		162		162	
yes		-5.1546		-12.5635**		-0.0136
Carer community support	167		167		167	
yes		-5.0360		-5.0477		0.7805*
Other care-recipients	167	1.0474	167	0.6246	167	-0.2000*
Age care-recipient	167	0.0711	167	0.3549	167	-0.0452
Other carers	167		167		167	
yes		-8.2214**		-3.9040		-0.2188
Gender care-recipient	167		167		167	
Female		4.9357		7.3017*		-0.6633
Dementia severity	165		165		165	
Moderate		-11.9531**		-11.8641**		0.1095
Severe		4.2375		2.4517		0.0388
Challenging behaviour care-recipient (NPI)	157	-0.2688*	157	-0.4055**	157	0.0461**
Carer-receipient medical services community	167		167		167	
yes		-1.1771		0.3002		0.1037
Care-recipient hospital	167		167		167	
yes		-1.5970		-2.4238		0.3350
Care-recipient community support	167		167		167	
yes		-13.872		-7.6454		-0.3115
Care-recipient daycare	167		167		167	
yes		-2.2540		-3.5839		0.5033

Table 5.5.3 MODEM complete case analysis focusing on carer and care-recipient characteristics (EQ-5D; GHQ; PWB1)

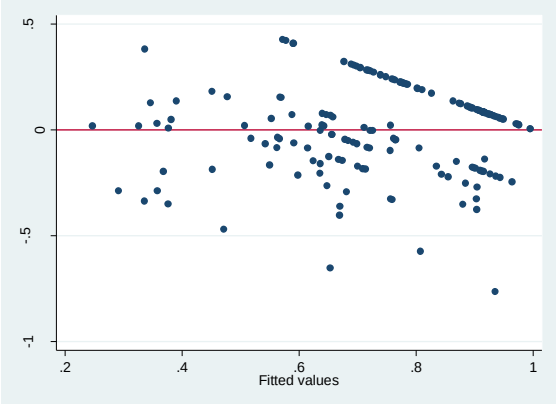
Variables	**EQ-5D 12**		**GHQ**		**PWB1**	
	N=165		N=167		N=163	
	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%
Carer gender						
Female	0.0340	-0.0821; 0.1501	0.2354	-0.2436; 0.7134	-6.7022	-19.7975; 6.3932
Carer age	0.0023	-0.0048; 0.0094	0.0419**	0.0133; 0.0706	0.1435	-0.6526; 0.9396
Relationship						
Filial carer	-0.0249	-0.2422; 0.1923	0.8032*	-0.0859; 1.6923	3.4539	-22.7056; 29.6135
Other unpaid	-0.0829	-0.3507; 0.1847	0.5623	-0.5468; 1.6615	16.9067	-19.9609; 53.7744
Co-residence						
Yes	-0.0711	-0.2143; 0.0720	-0.4410	-1.0264; 0.1443	7.5693	-8.5075; 23.6460
Age care-recipient	-0.0049	-0.0124; 0.0025	-0.0379**	-0.0681; -0.0078	0.4344	-0.4195; 1.2883
Gender care-recipient						
Female	-0.0026	-0.1164; 0.1112	-0.1552	-0.6334; 0.3121	4.8029	-8.5153; 18.1213
Dementia severity						
Moderate	-0.0199	-0.0954; 0.0556	0.1876	-0.1211; 0.4963	-7.3311*	-15.5367; 0.8746
Severe	0.0001	-0.1054; 0.1055	0.3094	-0.1195; 0.7383	-2.2422	-13.6212; 9.1368
Baseline value	0.5814***	0.4669; 0.6959	0.5993***	0.4666; 0.7320		
Constant	0.6099**	0.1933; 1.0265	0.5117	-1.1574; 2.1809	1.9292	-44.1915; 48.0498

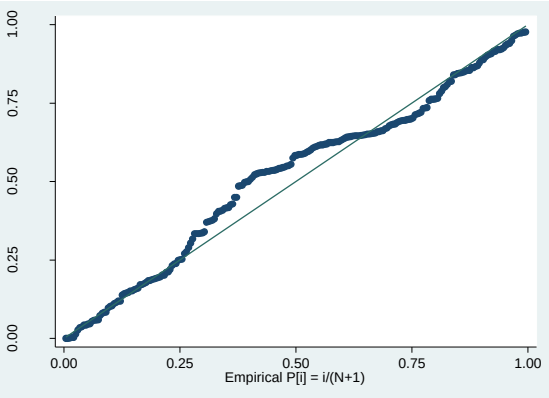
*p≤0.10 **p≤0.05 ***p≤0.001

Variables	**EQ-5D**	**GHQ**	**PW1**
	AIC= -25.78	AIC445.57	AIC=1501.51
	R2=0.4125	R2=0.3986	R2=0.0992

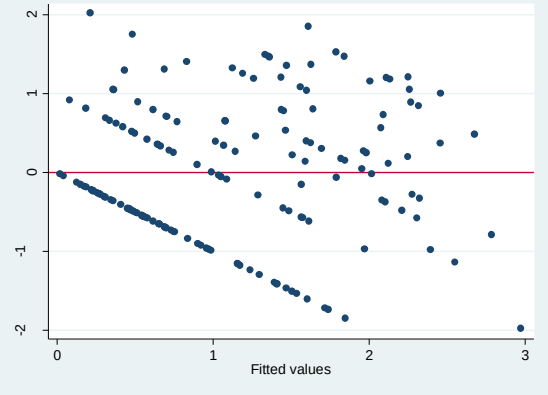
Box 6.5.3 Residuals

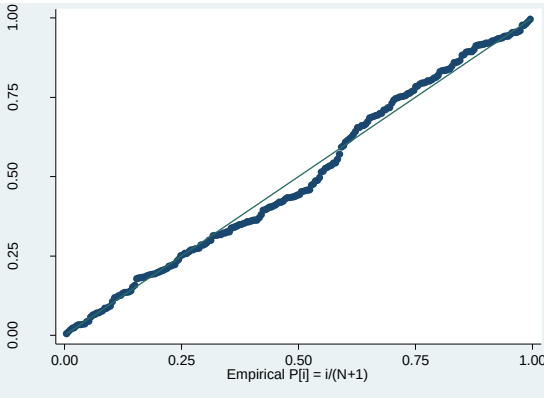
EQ-5D



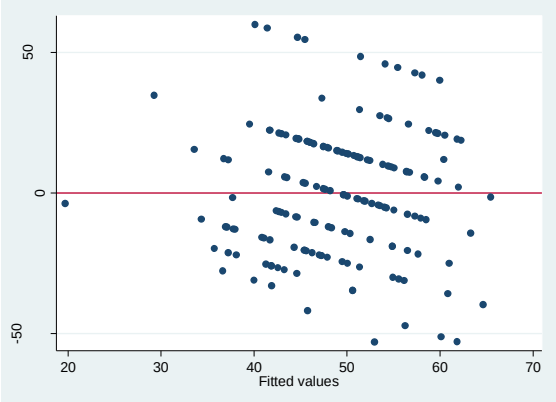


GHQ





PWB1



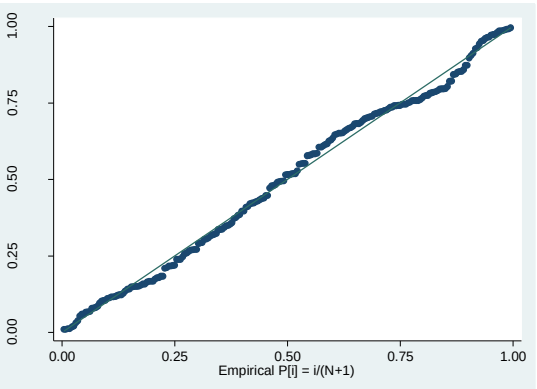


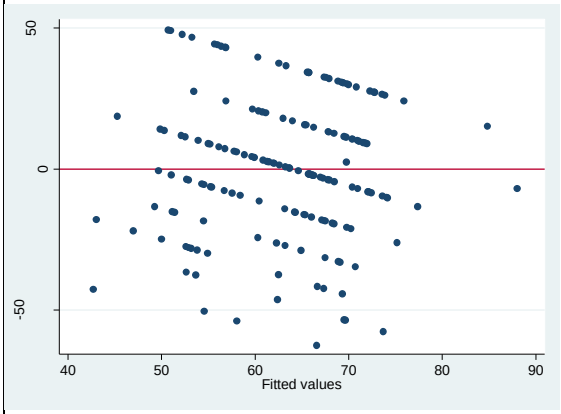
Table 5.5.4 MODEM complete case analysis focusing on carer and care-recipient characteristics (PWB2; PWB3; PWB4)

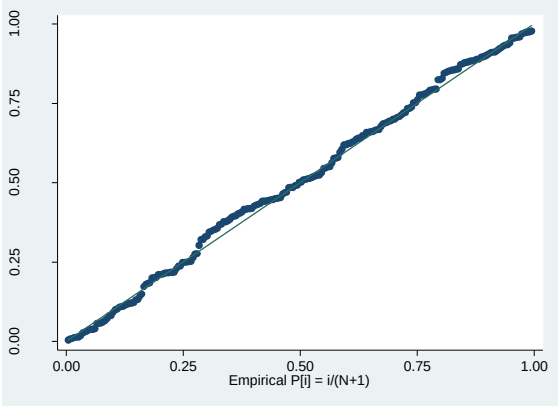
Variables	**PWB2**		**PWB3**		**PWB4**	
	N=164		N=164		N=164	
	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%
Carer gender						
Female	-4.9489	-19.1057; 9.2078	-5.0268	-19.6974; 0.6438	0.6826	-0.9885; 2.3537
Carer age	-0.2266	-1.0869; 0.6339	-0.3442	-1.2359; 0.5474	0.0179	-0.0837; 0.1195
Relationship						
Filial carer	-12.7289	-40.2922; 14.8343	-22.2535	-50.8172; 6.3103	-0.1451	-3.3987; 3.1085
Other unpaid	10.4248	-29.1522; 50.0019	14.4972	-26.5163; 66.5107	-1.7907	-6.4623; 2.8810
Co-residence						
Yes	1.9315	-15.1411; 19.0041	2.1094	-15.5828; 19.8017	-0.1470	-2.1623; 1.8682
Age care-recipient	0.5967	-0.3289; 1.5223	1.1017	0.1425; 2.0609	-0.0604	-0.1696; 0.0489
Gender care-recipient						
Female	2.7689	-11.4588; 16.9966	8.3099	-6.4342; 23.0540	-0.2186	-1.8980; 1.4608
Dementia severity						
Moderate	-11.7289**	-20.6353; -2.8953	-10.9316	-20.1236; -1.7396	0.0529	-0.9942; 1.0999
Severe	2.7678	-9.5723; 15.1079	1.5031	-11.2849; 14.2911	0.1008	-1.3558; 1.5575
Constant	37.7779	-12.0268; 87.5825	-2.5850	-54.1974; 49.0273	6.4702**	0.5913; 12.3492

Variables	**PWB2**	**PWB3**	**PWB4**
	AIC= 1537.39	AIC= 1549.09	AIC=836.55
	R2=0.0941	R2= 0.1379	R2=0.0423

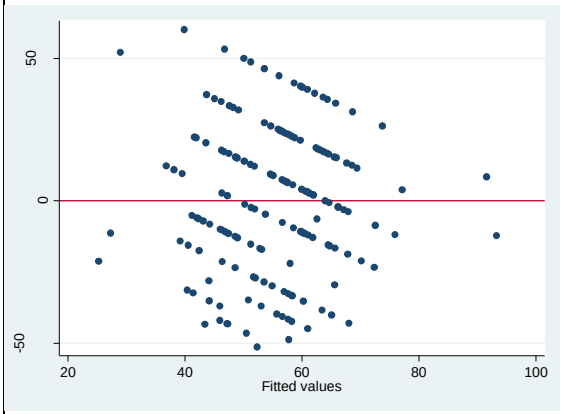
Box 6.5.4 Residuals

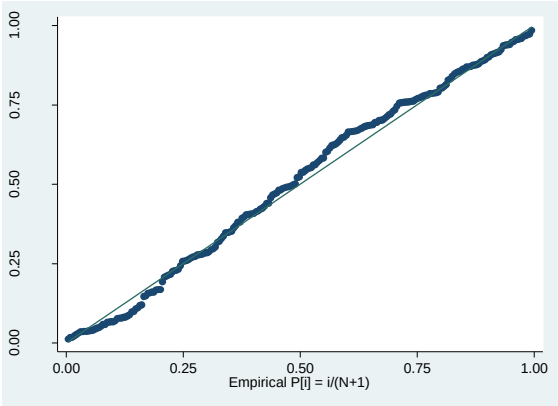
PWB2



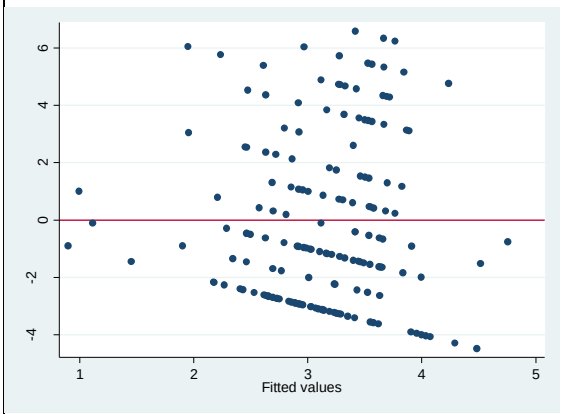


PWB3





PWB4



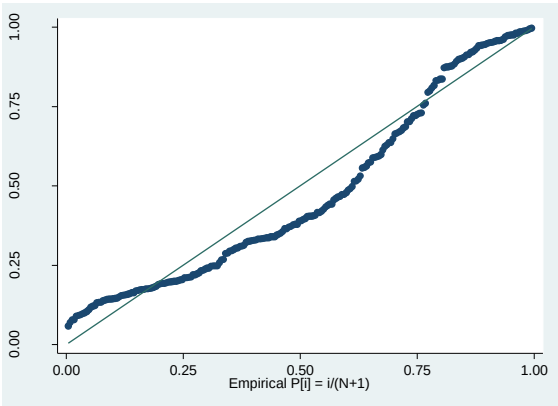


Table 5.5.5 Univariate analysis MODEM imputed analysis (EQ-5D; GHQ; PWB1)

Variables	**EQ-5D (12 months)**		**GHQ depression (12 months)**		**PWB1 (12 months)**	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	196		196		296	
Female		-0.0409		1.3491**		-9.0270
Carer age	196	-0.0010	196	-0.0137	196	0.2650
Relationship	196		196		196	
Filial carer		0.0014		0.4556		-1.4641
Other unpaid		-0.1174		0.3959		10.9296
Carer marital status	196		196		196	
Married		0.0872		-0.6161		4.4893
Divorced		-0.0736		0.8712		-10.7509
Widowed		0.2541		-0.6573		10.4815
Carer education	196		196		196	
Further education		-0.0258		-0.2350		-8.8389
Higher education		-0.0096		-0.1865		-5.7691
Other		-0.0645		0.4333		-0.4364
Carer employment	196		196		196	
Not working		-0.0828		-0.2052		3.6905
Co-residence	196		196		196	
Yes		0.0019		-0.7433		1.1456
Time care-recipient can be left alone	170		170		170	
less than 4 hours		-0.0281		-0.2994		-1.4879
4 hours to 8 hours		0.0943		-1.5524		6.8279
8 to 12 hours		0.1899		-1.0738		-13.7228
12 to 16 hours		-0.1018		-0.3174		9.8194
Hours per week spent caring	178	-0.0033	178	0.0491	178	-0.3772
Sleep-disruption	196		196		196	
yes		-0.0804**		1.2891**		-6.4983
OARS	196		196		196	
Mildly to moderately impaired social relationships		-0.0168		-0.8209		-6.6586
Severely and totally impaired social relationships		-0.1011		0.6406		-14.0622**
Zarit burden score	196	-0.0037**	196	0.0982***	196	-0.8062***
Carer health	196		196		196	
Good		-0.1233**		1.1128**		-11.5792**
Poor and very poor		-0.4244***		4.0312***		-29.4836***
Chronic illness	196		196		196	
yes		-0.2290***		1.5101**		-1.4832
Carer health affected	196		916		196	
yes		-0.0639		2.1032***		-12.9444**
AGG_MENT	196	0.0035*			196	0.3564**
AGG_PHYS	196	0.0133***			196	0.9377***
Carer counselling	196		196		196	
Yes		-0.2539**		3.5291**		-19.6446**
Carer cash	196		196		196	
yes		0.0334		1.1129		-1.5034
Carer allowance	196		196		196	
yes		-0.0918		1.3327**		-14.2447**
Carer community support	196		196		196	
yes		-0.0192		1.2396**		-6.2609
Other care-recipients	196	-0.0083	196	0.1574	196	-0.4379
Age care-recipient	196	-0.0028	196	0.0061	196	0.3296
Other carers	196		196		196	
yes		-0.0471		-0.0222		-1.1869
Gender care-recipient	196		196		196	
Female		0.0338		-0.9260*		9.4818**

Variables	EQ-5D (12 months)		GHQ depression (12 months)		PWB1 (12 months)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Dementia severity	194		194		194	
Moderate		-0.0337		0.7966		-6.0809
Severe		0.0358		0.1083		-2.0811
Challenging behaviour care-recipient (NPI)	183	-0.0022	183	0.0616***	183	-0.2876**
Care-receipient medical services community	196		196		196	
yes		-0.0564		1.0251**		0.4882
Care-recipient hospital	196		196		196	
yes		0.0066		0.8655*		0.1183
Care-recipient community support	196		196		196	
yes		-0.1225		0.7272		5.4069
Care-recipient daycare	196		196		196	
yes		-0.0083		0.7433		-6.7522*

Table 5.5.6 Univariate analysis MODEM imputed analysis (PWB2; PWB3; PWB4)

Variables	PWB2 (12 months)		PWB3 (12 months)		PWB4 (12 months)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer gender	196		196		196	
Female		-7.5529		-8.7128*		0.4483
Carer age	196	0.2164	196	0.3607	196	0.0108
Relationship	196		196		196	
Filial carer		-6.6069		-7.8367		-0.8143
Other unpaid		8.1145		12.8425		-1.1049
Carer marital status	196		196		196	
Married		9.4409		15.092		-0.2436
Divorced		-21.1139*		- 4.6038		-1.3663
Widowed		6.5151		26.7679		-2.0798
Carer education	196		196		196	
Further education		-6.7445		-14.2983**		0.0277
Higher education		-4.2868		-11.9494*		-0.3473
Other		-06391		- 9.1685		-0.1033
Carer employment	196		196		196	
Not working		6.3669		4.1294		0.5551
Co-residence	196		196		196	
Yes		2.5936		4.2546		0.6718
Time care-recipient can be left alone	170		170		170	
less than 4 hours		-10.3342*		-0.9110		-0.7443
4 hours to 8 hours		-5.8042		8.9418		-10.0391
8 to 12 hours		-7.1274		-21.0522		-0.2961
12 to 16 hours		-1.1607		14.4200		-0.3149
Hours per week spent caring	178	0.1391	178	-0.2569	178	0.0417
Sleep-disruption	196		196		196	
yes		-3.5823		-5.0687		0.1124
OARS	196		196		196	
Mildly to moderately impaired social relationships		-2.9679		-7.4363		0.5324
Severely and totally impaired social relationships		-10.4081*		-13.7522**		1.3501
Zarit burden score	196	-0.8089***	196	-0.8398***	196	0.0596***
Carer health	196		196		196	
Good		-6.2582		-10.4594**		1.4601**
Poor and very poor		-31.6484***		-26.7038***		1.7638**
Chronic illness	196		196		196	
yes		-8.3189*		-6.7538		0.6602

Variables	PWB2 (12 months)		PWB3 (12 months)		PWB4 (12 months)	
	n	Estimated coefficient	n	Estimated coefficient	n	Estimated coefficient
Carer health affected yes	196	 -8.4029*	196	 -12.8042**	196	 1.1257**
AGG_MENT	196	0.7991***	196	1.0477***	196	-0.1061***
AGG_PHYS	196	0.5808**	196	0.2806	196	-0.02006
Carer counselling Yes	196	 -195392**	196	 -21.5763**	196	 1.5777
Carer cash yes	196	 -6.4079	196	 -9.6069	196	 -0.4937
Carer allowance yes	196	 -6.5038	196	 -12.5167**	196	 -0.0442
Carer community support yes	196	 -6.0293	196	 -6.6808	196	 0.8372*
Other care-recipients	196	0.9999	196	0.4786	196	-0.2183*
Age care-recipient	196	0.1778	196	0.4530	196	-0.0448
Other carers yes	196	 -6.8046	196	 -2.2588	196	 -0.2778
Gender care-recipient Female	196	 5.8023	196	 7.4916*	196	 -0.6946
Dementia severity Moderate Severe	194	 -8.3691* 2.1315	194	 -10.0839** 0.5081	194	 0.0323 0.1360
Challenging behaviour care-recipient (NPI)	183	-0.2897*	183	-0.4398**	183	0.0451**
Care-receipient medical services community yes	196	 -1.2653	196	 0.2722	196	 0.1673
Care-recipient hospital yes	196	 -3.7851	196	 -2.6086	196	 0.1851
Care-recipient community support yes	196	 -12.5023	196	 -5.9506	196	 -0.4183
Care-recipient daycare yes	196	 -1.2163	196	 -3.5990	196	 0.4799

Table 5.5.7 MODEM imputed analysis focusing on carer and care-recipient characteristics (EQ-5D; GHQ; PWB1)

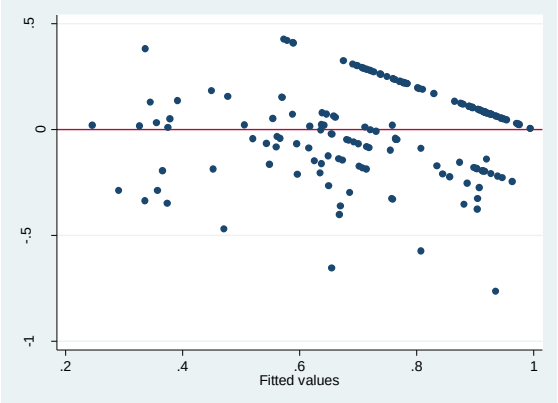
Variables	**EQ-5D 12**		**GHQ 12**		**PWB1**	
	N=194 (IM=20)		N=194		N=194	
	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%
Carer gender						
Female	0.0248	-0.0875; 0.1371	0.9277	-0.5128; 2.3682	-5.4503	-19.2654; 8.3649
Carer age	0.0022	-0.0051; 0.0094	0.0628	-0.0271; 0.1528	0.2909	-0.4939; 1.0756
Relationship						
Filial carer	-0.0279	-0.2509; 0.1951	1.5577	-1.0964; 4.2118	-1.4972	-26.1941; 23.1997
Other unpaid	-0.0804	-0.3213; 0.1605	1.7029	-106362; 5.0419	12.0997	-21.9181; 46.1175
Co-residence						
Yes	-0.0692	-0.2069; 0.0686	0.0869	-1.7318; 1.9056	-1.3234	-17.5123; 14.8654
Age care-recipient	-0.0042	-0.0117; 0.0032	-0.0669	-0.1549; 0.0211	0.3348	-0.5085; 1.1780
Gender care-recipient						
Female	0.0025	-0.1089; 0.1139	-0.1128	-1.5207; 1.2951	7.8059	-6.4082; 22.0201
Dementia severity						
Moderate	-0.0185	-0.0905; 0.0536	0.6147	-0.2992; 1.5287	-5.4189	-14.1375; 3.2995
Severe	0.0031	-0.1018; 0.1080	0.8892	-0.4003; 2.1746	--3.7895	-15.2099; 7.6309
Baseline score	0.5811***	0.4706; 0.6916	0.5881***	0.4463; 0.7298		
Constant	0.5679**	0.1656; 0.9703	0.5518	-4.4409; 5.5446	5.8886	-47.0900; 58.8673

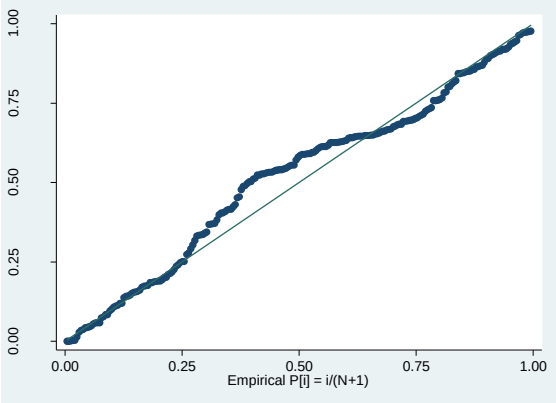
Variables	**EQ-5D MI=0**	**GHQ MI=0**	**PWB1 MI=0**
	AIC=-47.00	AIC=815.89	AIC=1511
	R2=0.414	R2=0.3815	R2=0.1012

Box 6.5.4 Residuals

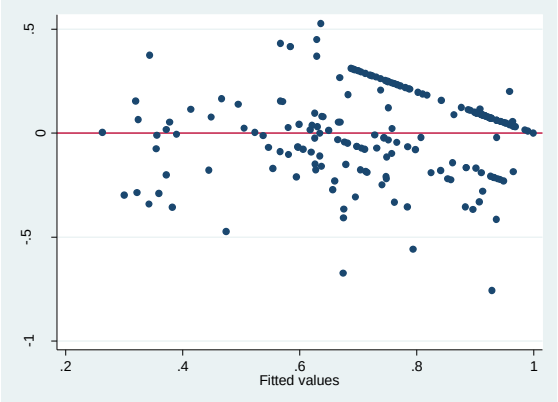
EQ-5D

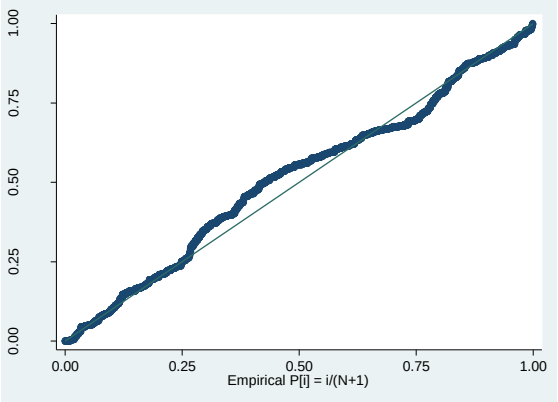
Imputation 0



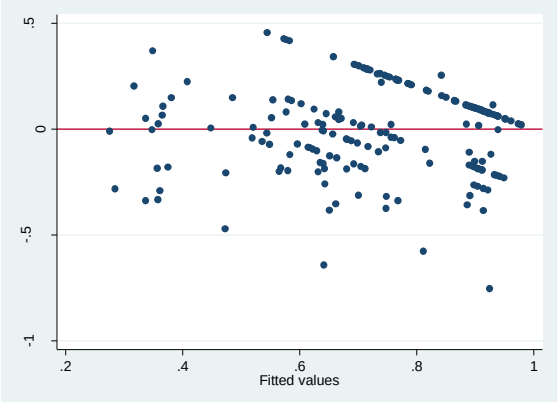


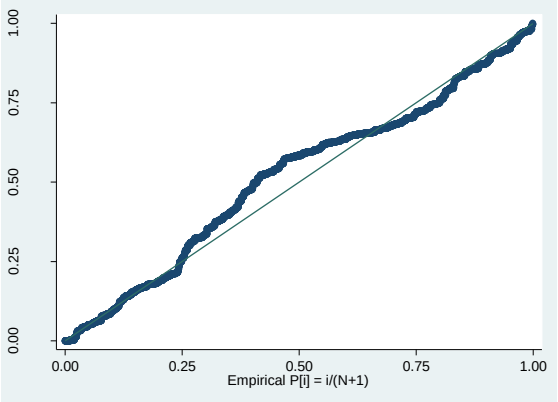
Imputation 4





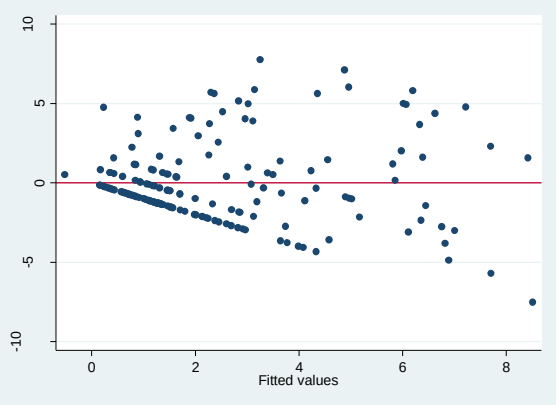
Imputation 15

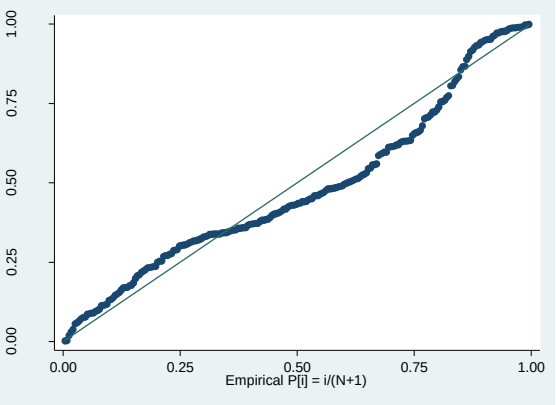




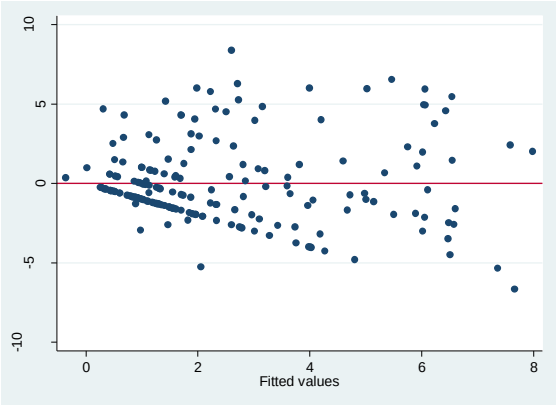
GHQ

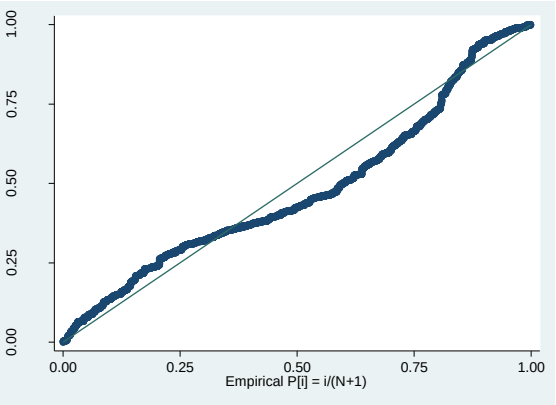
Imputation 0



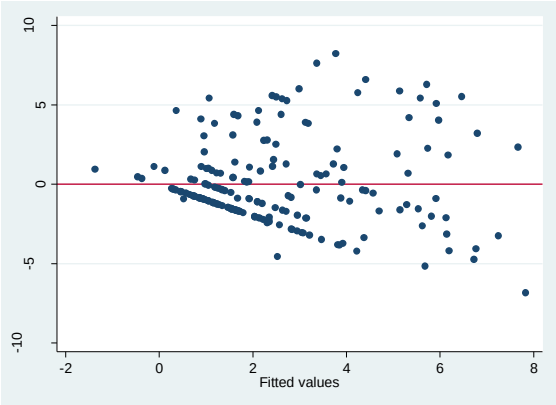


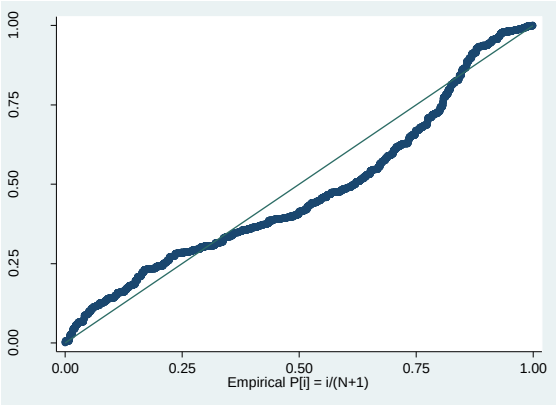
Imputation 4





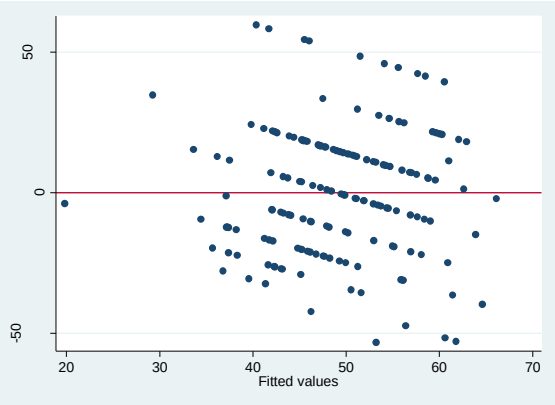
Imputation 15

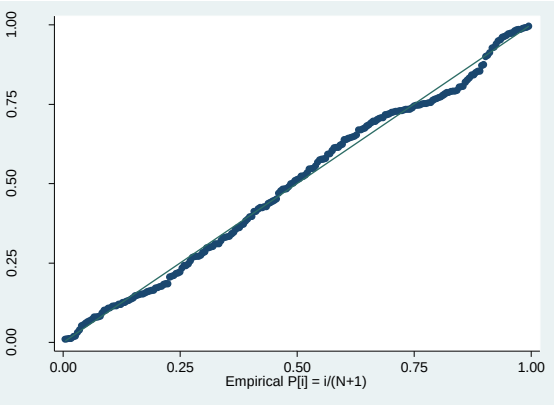




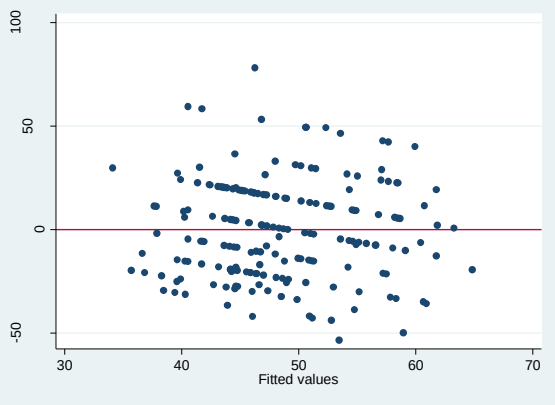
PWB 1

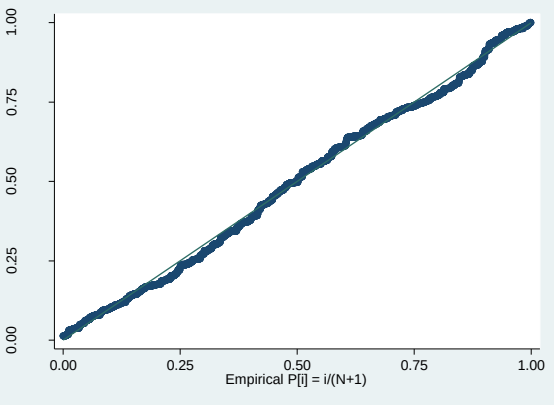
Imputation 0





Imputation 4





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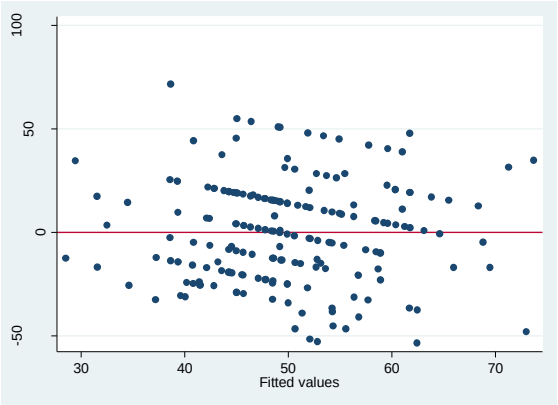


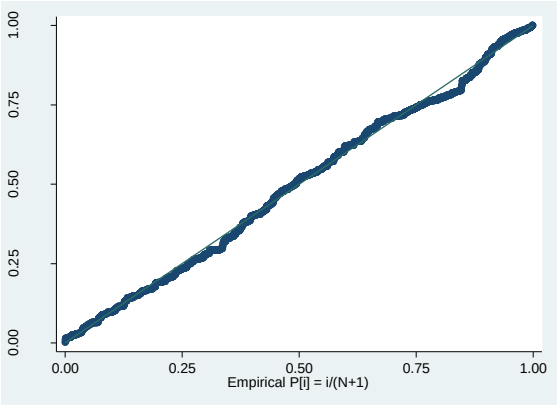


Table 5.5.8 MODEM imputed analysis focusing on carer and care-recipient characteristics (PWB2; PWB3; PWB4)

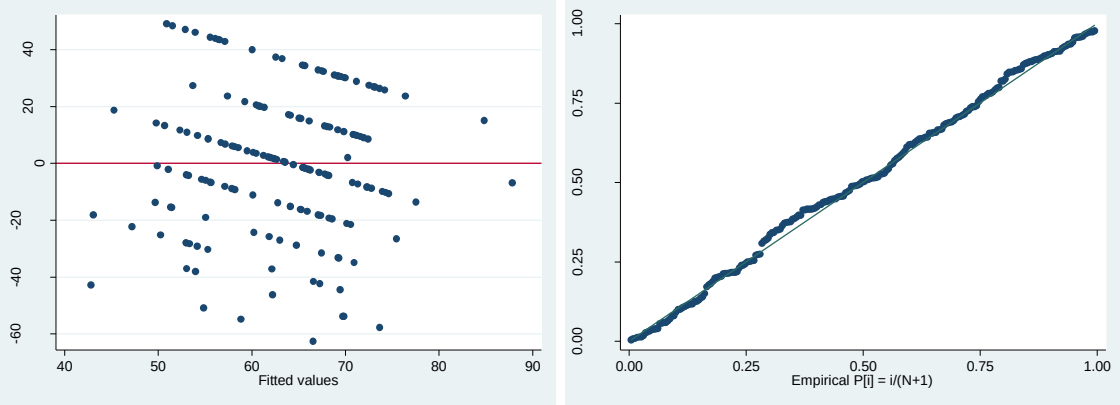
Variables	**PWB2**		**PWB3**		**PWB4**	
	N=194		N=194		N=194	
	Est. coeff.	CI 95%	Est. coeff.	CI 95%	Est. coeff.	CI 95%
Carer gender						
Female	-5.8860	-20.1650; 8.3929	-5.8447	-21.0983; 9.4089	0.5168	-0.9365; 2.3682
Carer age	-0.2653	-1.1431; 0.61151	-0.2347	-1.1737; 0.7043	0.0353	-0.0638; 0.1344
Relationship						
Filial carer	-20.9893	-48.0069; 6.0284	-23.7203*	-50.3113; 2.8707	0.3118	-2.9927; 3.6163
Other unpaid	- 1.8946	-33.0419; 29.2527	1.0369	-34.0749; 36.1489	-0.3202	-4.6667; 4.0264
Co-residence						
Yes	-5.4627	-23.1029; 12.1776	-3.5027	-22.5237; 15.5183	-0.0212	-2.0748; 2.0323
Age care-recipient	0.7296	-0.1736; 1.6329	1.0599**	0.1603; 1.9595	-0.0737	-0.1796; 0.0322
Gender care-recipient						
Female	5.7548	-9.0395; 20.5491	9.1749	-5.5519; 23.9018	-0.3010	-1.9612; 1.3591
Dementia severity						
Moderate	-7.9574	-17.4032; 1.4884	-9.6291**	-19.1025; -0.1557	0.0502	-0.9810; 1.0814
Severe	0.6217	-11.8076; 13.0510	-0.5999	-13.6308; 12.431	0.2942	-1.0942; 1.6826
Constant	36.5375	-14.8987; 89.9738	-1.0197	-54.6640; 526247	6.0396**	0.2002; 11.8791

Variables	**PWB2 MI=0**	**PWB3 MI=0**	**PWB4 MI=0**
	AIC=1546.35	AIC=0.1379	AIC=0.0423
	R2=0.0929	R2=1558.27	R2=840.5309

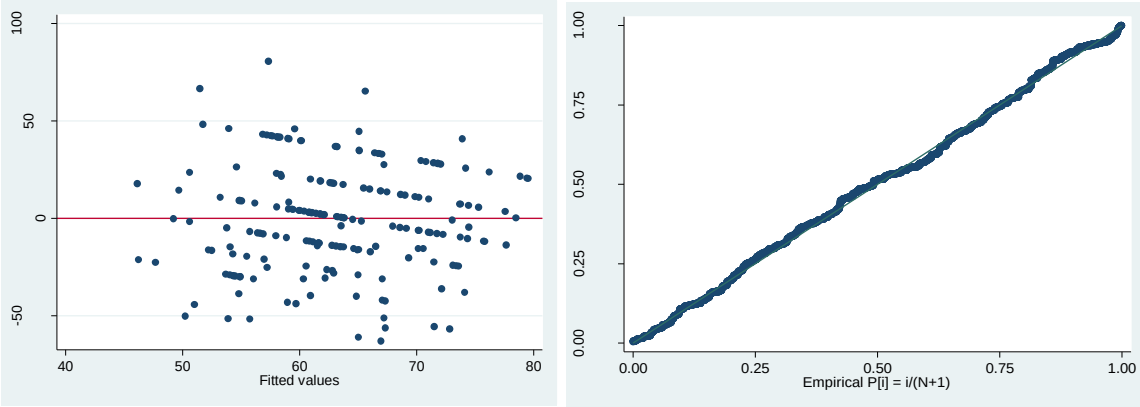
Box 6.5.4 Residuals

PWB2

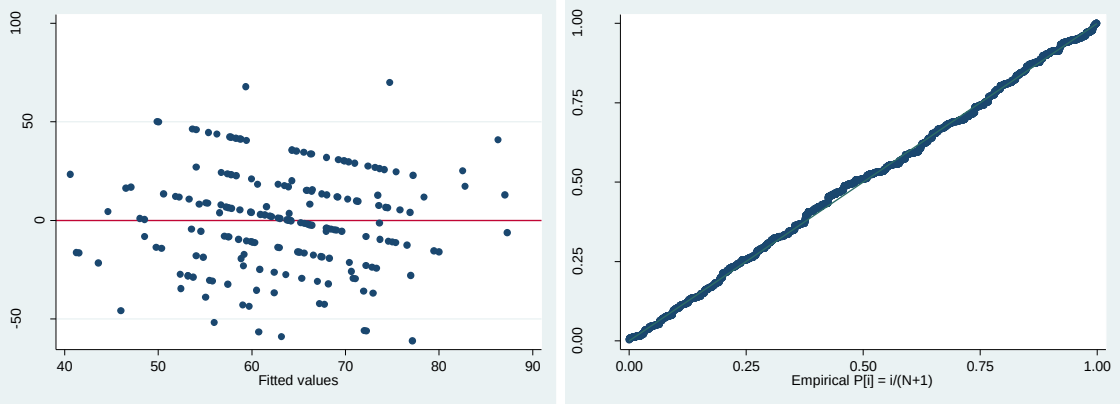
Imputation 0



Imputation 4

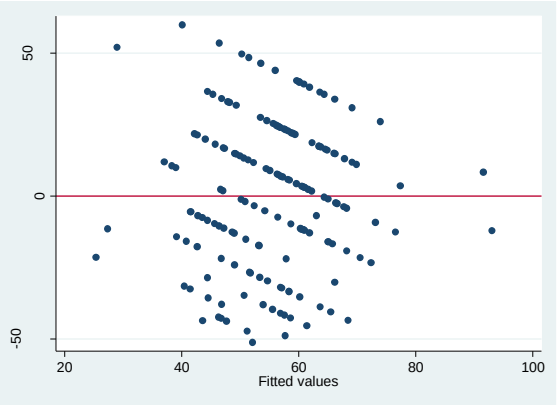


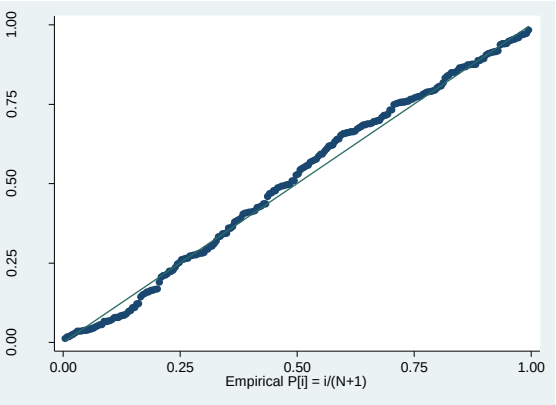
Imputation 15



PWB3

Imputation 0





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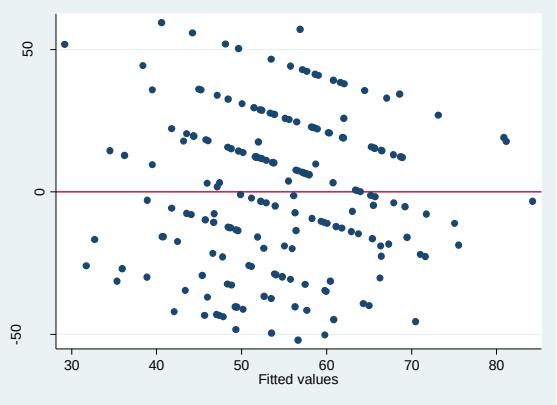

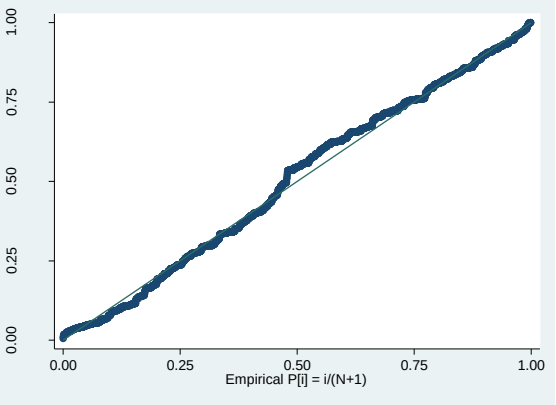

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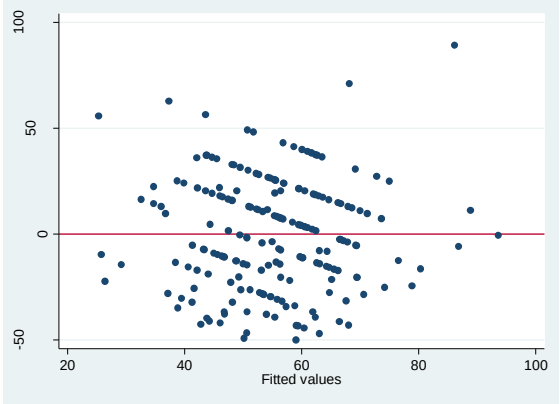
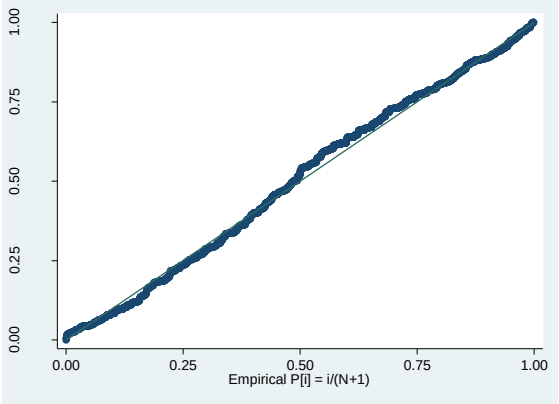
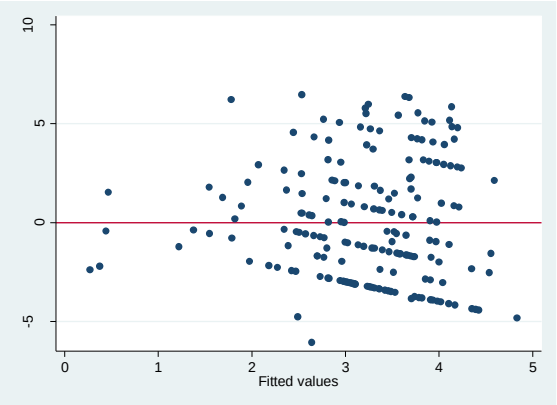
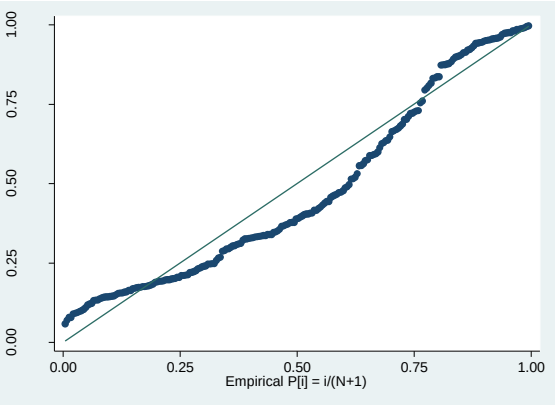




PWB4

Imputation 0





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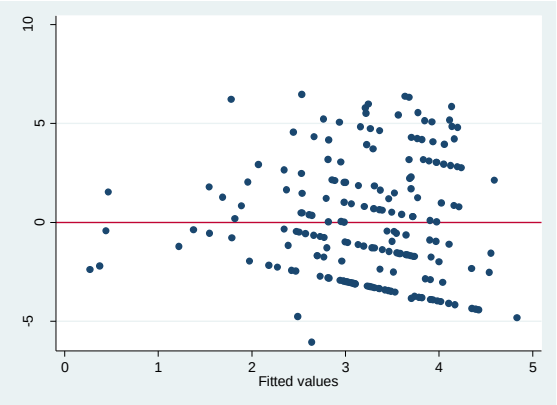

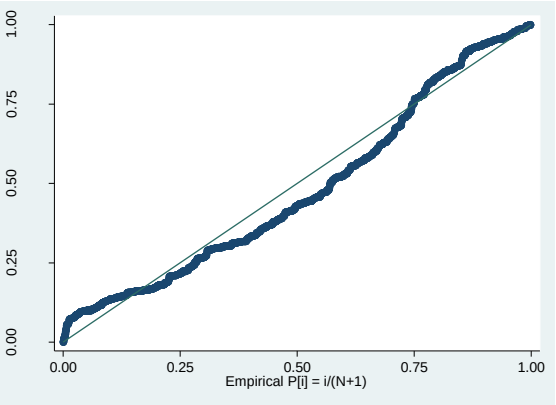

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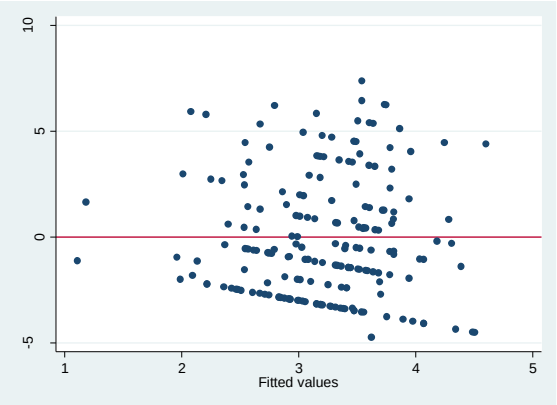

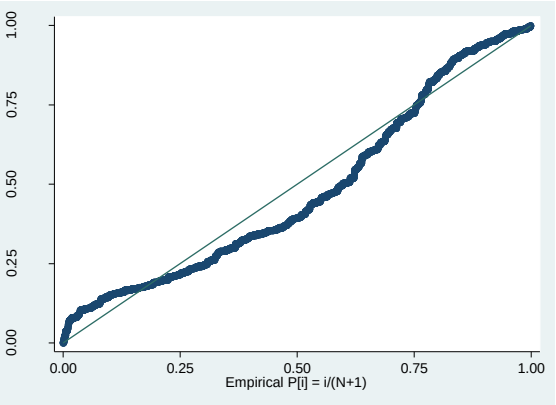

Appendix 6

6.1 the MODEM amended RUD questionnaire

1. In the question you just answered, you indicated that the person you care for requires support with activities of daily living. I would like to ask you a few more detailed questions on how much time over the last month you spend on specific activities.	
A. Are you the primary caregiver?	Yes No
B. Are you…	A formal carer? An unpaid carer?
C. Other than yourself, what other types of care does the participant receive?	Formal care Unpaid care None

2. Over the past month (when you have provided care to the person with dementia), how much time have you/ other carers spent helping (participant) with activities of daily living (ADLs)?					
Related to BADL item	ADLs	Support received from: (Delete as appropriate)	Were you the primary caregiver for this activity?	Time spent by unpaid carer	Time spent by formal carer
6,7,8	Personal hygiene (e.g. Bathing and washing)	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
9	Using the toilet	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
5	Dressing or undressing	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
2	Eating including cutting up food (nutrition)	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
10 or 11	Getting around indoors	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
11 or 20	Getting around outside the house	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days

3. If you are an unpaid carer … (otherwise go to Q4A)

A. Considering the previous activities (e.g. hygiene, toilet use, dressing, eating, and getting around). Over the last month, on how many days have you spent on help with these activities?
_____ days

B. Considering the previous activities (e.g. hygiene, toilet use, dressing, eating, and getting around). Over the last month, on how many days have formal carers provided help with these activities?
_____ days

4. If you are a formal carer…

A. Considering the previous activities (e.g. hygiene, toilet use, dressing, eating, and getting around). Over the last month, on how many days have you spent on help with these activities
_____ days

B. Considering the previous activities (e.g. hygiene, toilet use, dressing, eating, and getting around). Over the last month, on how many days have unpaid carers provided help with these activities?
_____ days

5. How much time have you/other carers spent helping (participant) with instrumental activities of daily living (IADLs)?

Related to BADL item	IADLs	Support received from: (Delete as appropriate)	Were you the primary caregiver for this activity?	Time spent by unpaid carer	Time spent by formal carer
1	Preparing food	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
16	Doing routine housework or laundry	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
20	Trans-portation	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
18	Helping with finances	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
17	Shopping for food	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days
Other	Taking (and preparing) medication	Formal/ Unpaid/ Both/ Not applicable	Yes No	Mins/ days	Mins/ days

6. If you are an unpaid carer … (otherwise go to Q7A)

A. Considering the previous activities (e.g. preparing food, housework, transport, finances, shopping and taking medication). Over the last month, on how many days have you spent on help with these activities?
_____ days

B. Considering the previous activities (e.g. preparing food, housework, transport, finances, shopping and taking medication). Over the last month, on how many days have formal carers provided help with these activities?
_____ days

7. If you are a formal carer…

A. Considering the previous activities (e.g. preparing food, housework, transport, finances, shopping and taking medication). Over the last month, on how many days have you spent on help with these activities
_____ days

B. Considering the previous activities (e.g. preparing food, housework, transport, finances, shopping and taking medication). Over the last month, on how many days have unpaid carers provided help with these activities?
_____ days

How much time have you/other carers spent on supervision?

[Supervision here refers to time spent with the person with dementia ensuring that the person is safe and happy, but doesn't require constant interaction or care activities. It is time the carer has to spend with the person with dementia but can also spend on activities such as watching television together, doing other household tasks or other activities]

8. If you are a formal carer … (otherwise go to Q9A)

A. How many hours of supervision did you provide on a typical day? _____ hours
B. Over the last month, on how many days have you provided supervision? _____ days
C. How many hours of supervision does an unpaid carer provide on a typical day?
_____ days
D. Over the last month, on how many days has an unpaid carer provided superivion?
_____ days

9. If you are an unpaid carer …

A. How many hours of supervision did you provide on a typical day? _____ hours
B. Over the last month, on how many days have you provided supervision? _____ days
C. How many hours of supervision does a formal carer provide on a typical day?
_____ hours
D. Over the last month, on how many days has a formal carer provided supervision?
_____ days

10. Consider the time spent supervising the person you care for. What percentage of this time can you also use for yourself (e.g. work related activity, leisure activity)?
_____ %

Appendix 7

6.1 Carer Well-being study protocol

MODEM: carer wellbeing study

February 01, 2016

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Tel. 020 7955 6259

I. Background

Dementia is a syndrome requiring high levels of care and supervision and has been described as "the leading chronic disease contributor to disability and need for care" (Wimo et al., 2013, p.1). Partners, relatives and friends in the community provide most of this care. Constantly changing needs of the person with dementia throughout the dementia path, potential development of neuropsychiatric disorders and behavioural changes require the unpaid carer to adapt and develop new skills over time (De Vugt and Verhey, 2013). Unpaid carers for people with dementia therefore require specific study to better understand which aspects of providing care influence the experience as a carer and affect their wellbeing.

Most care literature focuses on the negative implications of the provision of unpaid care. Particularly in dementia care, it has been shown that carer burden and the presence of mental and physical health problems in carers is high (Ory et al., 1999, Vitaliano et al., 2003, Pinquart and Sörensen, 2007). Findings on the impact of age and gender on physical and mental health outcomes in carers are mixed (Kim et al., 2012, Ory et al., 1999, Vitaliano et al., 2003, Croog et al., 2006, Papastavrou et al., 2007b, Mitrani et al., 2006). Despite the growing body of information on carer burden, many people providing unpaid care for their partner, relative or friend with dementia also report positive aspects of the provision of care, a sense of responsibility, the feeling of doing something good and right (Pretorius et al., 2009, Sampson and Clark, 2015). Furthermore, with growing numbers of people living with dementia, the number of people providing dementia care is expected to increase over the next decades (Prince et al., 2014, p.45, Pickard et al., 2007). A better understanding of determinants of wellbeing of male and female unpaid carers aged below and above retirement age for people with dementia could therefore contribute to a better understanding of carer needs and how these needs may differ between gender and age groups.

In most societies, care traditionally falls into the female realm (Sevenhuijsen, 1998, p.vi, Folbre, 2001, p.5, Bubeck, 1995, p.25, Browne, 2010). Feminism has brought the social phenomenon of women providing the bulk of unpaid care to the surface. The movement of emancipation, social and cultural changes over the last century have brought about important changes in what is deemed social norm. Women in England contribute to an important and growing share of the labour force (ONS, 2013a). Despite these developments, women still provide the majority of unpaid care work. The largest share of women in England providing unpaid care is aged between 50 and 64 years (ONS, 2013b). Women in this age group

providing unpaid care are more likely than men to leave employment to care for a relative, with implications for economic independence and pension claims (King and Pickard, 2013). The focus on unpaid female carers in the literature therefore is important.

However, over recent decades, increasing male life expectancy and a shift in the understanding of traditional male and female tasks in the household have led to a situation where not just more older men are alive and in the position to care for their parent or partner, but also take up these care tasks. According to population Census statistics, the proportion of men providing unpaid care increases particularly after the age of 65 and even exceeds the share of unpaid care provided by women (ONS, 2013b, Croog et al., 2006). While female life expectancy remains above male life expectancy, women also are more likely to spend more years in health declared as "Not Good" (ONS, 2013b). This may further influence a situation where men have to provide unpaid care to their partner in older age. The increasing share of unpaid care provided by men creates the need to investigate the care experience and wellbeing of unpaid male carers.

Feminist theory continues to dominate the care literature. This may have implications for how carer experience and care responsibility are constructed and reported. The literature reports inconsistent findings regarding the burden experienced by male carers (Croog et al., 2006, Vitaliano et al., 2003). The 2011 Census, however, shows that carer health worsens for both men and women with increasing hours of care provided. The worst general health has been reported for carers providing care for 50 or more hours per week, with 41.7% of women and 46.6% of men reporting not to be in good general health when providing this intensity of unpaid care (ONS, 2013b). The large proportion of men reporting health problems further increases the need to better understand the male care experience and concepts of wellbeing. Investigating qualitative aspects of unpaid caregiving related to carer wellbeing can contribute important insights to a better understanding of factors influencing carer wellbeing.

II. Aims

The objectives of this study are

1. to learn how carers for people with dementia understand wellbeing and their expectations for what it means to be well.

2. to investigate whether aspects considered important for the wellbeing of carers differ for men and women.
3. to investigate whether aspects considered important for the wellbeing of carers differ between people above and below retirement age.
4. to compare and contrast findings of this qualitative study with findings from questionnaires frequently used to measure aspects of carer wellbeing.

III. Method

a. Inclusion and Exclusion Criteria

Inclusion and exclusion criteria are consistent with the MODEM cohort study as participants will be members of this study.
Inclusion: Furthermore, participants and the person with dementia they provide care to have to reside in the community.

Exclusion: The inability to communicate in English is an exclusion criterion for this study. Also, the residence of the person with dementia the interviewee is looking after in an institution is an exclusion criterion for this study.

b. Recruitment

Potential interviewees will be identified from the MODEM cohort study. Only members of the MODEM study who have indicated in their consent form that they would like to be re-contacted for further studies will be contacted.

Potential participants will be informed by post about the study. Potential participants will be followed-up by the principal investigator by telephone to provide further information and to arrange a suitable time and place for the interview. Potential interviewees will be offered a visit in their homes. Potential interviewees can choose to opt-out prior to the telephone follow-up by contacting the principal investigator by telephone or e-mail. At the interview the principal investigator will explain the study. If potential participants provide consent, the interview can be conducted.

c. Ethical issues

This qualitative study will benefit from the extensive knowledge and experience of senior researchers involved in this project as academic supervisors and key collaborators.

All participants recruited for this study will be unpaid carers who also are participants in the MODEM cohort study and with the capacity to provide informed consent.

Only unpaid carers who have provided consent to this study will be interviewed, however, it has been anticipated that carers may provide information about the person with dementia they look after. Because of this carers will be encouraged to discuss their participation with the person they care for. Furthermore, potential personal identifiers will be removed from the transcripts prior to analysis.

Unpaid carers for people with dementia may experience strain and stress due to their care responsibility. Participation in this study may add to the stress due to the time necessary to engage with the project. This burden will be minimised by offering potential participants to interview them in their home or another place of their convenience.

Participating carers may experience participation in the interview as intrusion into their personal lives. The interview touches on topics carers may perceive as sensitive and personal. These include questions on the support carers receive from family and friends, feelings of loneliness, carer physical health, self-esteem, financial implications experienced due to the care situation and on their sexual relationship if the person with dementia is the carers partner.
Prior to the interview carers will have been informed about the topic areas that will be discussed. Furthermore, the carer can indicate at any time that she or he would not like to respond to a question, that she or he can take a break at any time as well as the she or he has the ability to terminate the interview. These decisions will be respected at any time.

Carers will have been informed prior to the interview that any information they provide is confidential. They will further be informed that confidentiality may only be broken if the interviewee provides me with information that indicates risk or harm to the carer or the person with dementia. If serious harm or abuse is reported or observed by me during testing,

a standardized procedure will be followed. Following this procedure requires that I will immediately notify the clinical lead of the MODEM cohort study (Prof Sube Banerjee) who will in turn notify the relevant clinical services responsible for the patient, enabling them to take appropriate action. In circumstances where the participant or carer is in imminent danger, I will contact the emergency services.

Finally, audio recordings, field notes and transcripts contain sensitive information. This data will be stored at the London School of Economics and Political Science (LSE) according to LSE data regulations and in accordance with the UK data protection legislation. Only I will have access to personal information containing addresses of participants, audio recordings and anonymised and transcribed documents. Documents containing information that could lead to identification of participants will be stored separately from each other and separately from anonymised transcripts.
Other PSSRU at LSE researchers may have access to anonymised transcripts to provide advice with analysis.
LSE computers are password protected and as the locked cabinets in which physical files will be stored are located in buildings that outside work hours only can be accessed using LSE identity cards and/or codes.

a. Qualitative Interviews

Qualitative interviews will be conducted following the framework of the topic guide developed for this study. The topic guide includes questions on the four-topic areas care experience, gender aspects, age aspects and wellbeing. These four topics will be covered with all participants; however, the extent and use of specific questions may vary, allowing room for the exploration of issues the interviewees may provide.

b. Sample Size

For this qualitative study a total of 30 participants will be purposively sampled from the MODEM cohort.

As outlined in the sample matrix below, the study aims to include 30 participants, of which at least 14 participants will be male and 14 female. Literature on qualitative in-depth interviews and qualitative studies commonly recommend the sampling of about 30 participants in studies where the iterative sampling associated with grounded theory may be unfeasible due to time

and financial constraints and where neither very high levels of heterogeneity are expected nor the need for detailed sub-group analysis is required (Ritchie et al., 2014, pp.115-118). Comparison groups have been designed to "reflect the diversity of its own parent population" as well as possible while ensuring reasonably large group size (Lewis and McNaughton Nicholls, 2014, p.65).

In both gender groups I will aim to have at least 6 participants who are below age 65 and at least 6 participants who are above age 65. Investigating the care experience and perceptions of wellbeing between gender and age groups are the main objectives of this study. An equal split between participants in the different subcategories is therefore important to ensure sufficient representation in order to map the full range and diversity of factors across each of these participant characteristics.

Furthermore, a minimum of six spouse and adult child carers each will be sampled in the male and female group. Spouses and adult children make up the main groups of unpaid carers for people with dementia, a representation of both carer groups in each gender group is considered important.

In order to gain insight into potentially different care experiences depending on the current stage of dementia, a minimum of two carers will be recruited for the mild and moderate stages each in either gender groups. At least one carer for a person with severe dementia will be recruited. The pool of participants from which this subsample can be drawn is expected to be smaller as the number of unpaid carers providing care for people with severe dementia tends to be lower, as more people enter institutional care at advanced stages of dementia. Also the willingness or ability to contribute to research may decline with greater care needs.

Sampling matrix for qualitative study

Sample matrix	**Gender**	**Female**	**Male**
Age	<65 years	Min 6	Min 6
	>65 years	Min 6	Min 6
Relationship to person with dementia	Spouse	Min 6	Min 6

	Adult child	Min 6	Min 6
Stage of dementia	Mild Moderate Severe	Min 2 Min 2 Min 1	Min 2 Min 2 Min 1
Total		30	

a. Timetable

Qualitative interviews will be conducted between June and October 2016.

IV. Funding and Resources

The study and my PhD are funded by the Economic and Social Research Council (ESRC).

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Appendix 8

8.1 Approval letter

NHS
Health Research Authority
Social Care REC
Ground Floor
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 797 22567

19 April 2016 - Letter reissued on 26 April 2016 as the. original and revised version of the consent form and PIS had been included

Ms Klara Lorenz
Personal Social Services Research Unit at London School of Economics and Political Science
Houghton Street
London
WC2A 2AE

Dear Ms Lorenz

Study title:	**MODEM carer wellbeing study: the wellbeing of men and women aged below and above retirement age providing unpaid dementia care**
REC reference:	**16/IEC08/0012**
IRAS project ID:	**195399**

Thank you for your letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information. or wish to make a request to postpone publication, please contact the REC Manager,

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.
You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated

version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Public Liab and Employer Liab certificate [1]]	1	01 February 2016
Interview schedules or topic guides for participants [Interview_guide_23]	23	09 February 2016
Interview schedules or topic guides for participants [Interview_guide_24_SCREC]	24	26 March 2016
IRAS Checklist XML [Checklist_03022016]		03 February 2016
IRAS Checklist XML [Checklist_14022016]		14 February 2016
IRAS Checklist XML [Checklist_05042016]		05 April 2016
Letters of invitation to participant [invitation_letter_8]	8	09 February 2016
Other [Training for qualitative research skills]	1	01 February 2016
Other [Grundy_E_CV]	1	01 February 2016
Other [Martin Knapp_CV]	1	01 February 2016
Other [For_further_information_leaflet_4]	4	09 February 2016
Other [Telephone_Guide_3]	3	09 February 2016
Other [Thankyouletter_non_participants_7_SCREC]	7	27 March 2016
Other [For_further_information_leaflet_6]	6	26 March 2016
Other [letter_ethics committee_SCREC]	1	26 March 2016
Other [Revision QA6-1_SCREC]	1	26 March 2016
Other [Support with communication problems_SCREC]	1	26 March 2016
Participant consent form [Consentform_14_SCREC]	14	26 March 2016
Participant information sheet (PIS) [PIS_12_SCREC]	12	26 March 2016
REC Application Form [SC_Form_14022016]		14 February 2016
Referee's report or other scientific critique report [Klara Lorenz comment from educational advisor]	1	01 February 2016
Research protocol or project proposal [MODEM_carerWB_protocol_2]	2	09 February 2016
Summary CV for Chief Investigator (CI) [CV_Klara Lorenz]	1	01 February 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

16/IEC08/0012	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Chair

Enclosures: "After ethical review – guidance for researchers"

Copy to:

Appendix 9

Table 7.2.5.1 Support for family carers received by severity

	Husband	Wife	Son	Daughter	Other
Activities of daily living					
Personal hygiene					
mild	1 (1.47%)	8 (7.08%)	2 (15.38%)	1 (2.5%)	
moderate	6 (8.82%)	23 (20.25%)	1 (7.69%)	9 (22.5%)	
severe	21(30.88%)	16 (14.16%)	2 (15.38%)	4 (10.0%)	1 (10.00%)
Toileting					
mild		3 (2.65%)			
moderate	1 (1.47%)	9 (7.96%)	1 (7.69%)	6 (15.0%)	
severe	15 (22.06%)	8 (7.08%)	2 (15.38%)	2 (5.00%)	1 (10.00%)
Dressing					
mild	4 (5.88%)	13 (11.5%)	1 (7.69%)	3 (7.5%)	
moderate	7 (10.29%)	28 (24.78%)	1 (7.69%)	10 (25.0%)	2 (20.00%)
severe	21 (30.88%)	14 (12.39%)	3 (23.08%)	5 (12.5%)	1 (10.00%)
Eating					
Formal	1 (1.47%)	2 (1.77%)		2 (5.00%)	
Unpaid	1 (1.47%)	6 (5.31%)		5 (12.50%)	1 (10.00%)
Both	18 (26.47%)	5 (4.42%)	1 (7.69%)	3 (7.5%)	1 (10.00%)
Indoors					
mild	4 (5.88%)	3 (2.65%)			
moderate	3 (4.41%)	6 (5.31%)		7 (17.5%)	3 (30.00%)
severe	12 (17.65%)	3 (2.65%)	2 (15.38%)	1 (2.5%)	2 (20.00%)
Outdoors					
mild	7 (10.29%)	18 (15.93%)	2 (15.38%)	6 (15.00%)	2 (20.00%)
moderate	6 (8.82%)	25	2 (15.38%)	13 (32.5%)	2 (20.00%)
severe	19 (27.94%)	10 (8.85%)	3 (23.08%)	4 (10.0%)	1 (10.00%)
Instrumental activities of daily living					
Preparing food					
mild	12 (17.65%)	27 (23.89%)	2 (15.38%)	8 (20.00%)	
moderate	10 (14.71%)	31 (27.43%)	1 (7.69%)	12 (30.00%)	1 (10.00%)
severe	26 (38.24%)	16 (14.16%)	5 (38.46%)	7 (17.5%)	2 (20.00%)
Housework					
mild	13(19.12%)	27 (23.89%)	3 (23.08%)	8 (20.00%)	1 (10.00%)
moderate	9 (13.24%)	30 (26.55%)	1 (7.69%)	14 (35.00%)	4 (40.00%)
severe	26 (28.24%)	14 (12.39%)	5 (38.46%)	6 (15.0%)	2 (20.00%)
Transportation					
Formal	10 (14.71%)	23 (20.25%)	3 (23.08%)	12 (30.0%)	
Unpaid	10 (14.71%)	24 (21.24%)	3 (23.08%)	15 (37.5%)	3 (30.00%)
Both	22 (32.35%)	13 (11.5%)	4 (30.77%)	4 (10.00%)	1 (10.00%)
Finances					
mild	14 (20.59%)	28 (24.78%)	2 (15.38%)	13 (32.5%)	2 (20.00%)
moderate	10 (14.71%)	33 (29.20%)	3 (23.08%)	14 (35.00%)	4 (40.00%)
severe	25 (36.76%)	13 (11.5%)	4 (30.77%)	5 (12.5%)	3 (30.00%)
Shopping					
mild	17 (25.00%)	37 (32.74%)	3 (23.08%)	11 (27.5%)	2 (20.00%)
moderate	13 (19.12%)	36 (31.86%)	2 (15.38%)	16 (40.00%)	4 (40.00%)
severe	26 (38.24%)	17 (15.04%)	5 (38.46%)	7 (17.5%)	3 (30.00%)
Medication					
mild	14 (20.59%)	40 (35.39%)	3 (23.08%)	9 (22.5%)	
moderate	11 (16.18%)	38 (33.63%	1 (7.69%)	15 (37.5%)	3 (30.00%)
severe	26 (38.24%)	17 (15.04%)	2 (15.38%)	7 (17.5%)	2 (20.00%)
Total number of carers	68	113	13	40	10